

# **National Conference on Minority Health Research and Research Training**

Office of Minority Health  
Resource Center  
PO Box 37337  
Washington, DC 20013-7337

**March 27-30, 1994  
Chicago, Illinois**

**ORMH**  
OFFICE OF RESEARCH  
ON MINORITY HEALTH







NATIONAL INSTITUTES OF HEALTH

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Minority Health  
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## *EXECUTIVE SUMMARY*

The NIH Office of Research on Minority Health (ORMH) coordinates overall NIH policies and programs for improving minority health status and expanding the participation of minorities in biomedical research careers. It serves as principal advisor to the Director of NIH on minority issues and acts as a liaison to the health, biomedical research, education, and minority communities and to Congress on minority health and research issues. The current ORMH research agenda is the outcome of a wide-ranging consultative process that began in 1991 with three regional conferences. A Fact-Finding Team (FFT) representing a cross-section of those taking part in the consultative process composed a report to the Director of NIH which contained 13 recommendations from the community to guide the initial efforts of the ORMH. (The FFT's recommendations are attached as Appendix I.)

More recently, the ORMH sponsored the National Conference on Minority Health Research and Research Training in Chicago, Illinois on March 27-30, 1994. Participants in this Conference included 350 members of the minority biomedical community, more than half of whom were from the Midwest. The conference had the following goals: (1) to inform the various ORMH constituencies of the progress that had been made in response to the recommendations of the 1991 Fact-Finding Team; (2) to solicit feedback on those achievements; and (3) to obtain further information on the needs of minority populations in order to design responsive new ORMH programs for the years 1995-2000. As in 1991, an expert panel was appointed to write a report and make recommendations to the ORMH based on the conference deliberations. This 43-member panel, known as the Assessment Team (Appendix II), included members of the 1991 FFT as well as new members who brought a fresh perspective to the task of evaluating the accomplishments and future direction of the ORMH and the NIH in regard to minority health and training programs.



The consensus of the participants, as expressed in their responses to a Conference evaluation questionnaire, was (1) that ORMH personnel have been receptive to input from the community; (2) that the ORMH has made good progress in generating programs responsive to the original 13 FFT recommendations for minority health research and training; and (3) that the ORMH has increased awareness of minority concerns at all levels of the NIH. The participants agreed that the ORMH should continue to encourage NIH Institutes, Centers, and Divisions (ICDs) to fund more minority research and to collaborate with other government agencies to leverage funds dedicated to minority programs. Over three-quarters of the Conference participants felt that ORMH is achieving its dual goals of increasing research on diseases affecting minority groups and involving more minorities in biomedical research.

This report summarizes the Conference proceedings and presents recommendations based on the discussions and views expressed during the meeting. (Abstracts of Conference presentations are attached as Appendix III.) The community expressed strong support for the continued pursuit of the original 13 FFT recommendations. It recommended additional efforts in the areas of behavioral and social science research, minority institution infrastructure development, data collection and dissemination, community outreach, and collaboration with governmental and nongovernmental entities. The community emphasized that the ORMH should function as a strong trans-NIH office with responsibility for the coordination and review of all NIH minority health and training programs. To assist the ORMH in the development of its programmatic initiatives, the community recommended the formation of an external Advisory Committee.



## INTRODUCTION

### *The ORMH: Its Mission and Agenda 1990 to 1994*

The Office of Research on Minority Health (ORMH) was established by the Director of the National Institutes of Health (NIH) in 1990 and authorized by Congress in 1993. Its mission is two-fold: (1) to promote research aimed at improving the health status of minority Americans across the lifespan, and (2) to expand the participation of minorities in all phases of biomedical and behavioral research. The ORMH strategy for accomplishing this mission is to build partnerships with the Institutes, Centers, and Divisions (ICDs) of the NIH, as well as with other Federal agencies and outside organizations.

The ORMH and its Director, John Ruffin, Ph.D., are committed to the principle that effective policy is made from the ground up, not from the top down: that policymaking should be both a result of and a response to consultation with constituencies involved in the issues or processes that are the subject of policymaking. The current ORMH research agenda is the outcome of a wide-ranging consultative process that took place during 1991. Three regional conferences were held throughout the country in which almost 700 people—from colleges and universities, professional organizations in health and the life sciences, community-based organizations, Federal agencies, and the biotechnology industry—participated. A Fact-Finding Team (FFT), consisting of 54 eminent individuals who represented a cross-section of those taking part in the consultative process, was appointed to report on the deliberations at the three regional conferences.

The 1991 *Minority Programs Fact-Finding Team Report* includes 13 recommendations for specific actions that the ORMH and NIH should take to improve minority health status and expand minority participation in biomedical research. (The FFT's recommendations are attached as **Appendix I.**) In response to these recommendations, the ORMH has initiated over 100 funded activities that address important issues in minority health and minority research training.



## *The Minority Health Initiative*

The centerpiece of the ORMH agenda is the Congressionally mandated Minority Health Initiative (MHI), launched in Fiscal Year (FY) 1992 and funded at \$54.8 million in FY 1994. The MHI is a multi-component plan, designed to strengthen the NIH's commitment and responsiveness to the health research and training needs of minority Americans by building on previous NIH efforts to improve the overall health of minorities and to train more minority biomedical researchers.

The goals of the MHI include increasing intramural and extramural research aimed at improving minority health across the lifespan, developing protocols for intervention in health behaviors affecting the longevity and quality of life for minorities, and implementing programs that prepare more minorities for careers in the biomedical sciences. In FY 1993, the ORMH successfully completed the launching of the MHI.

New NIH studies in minority health research that have been initiated as part of the MHI include: Cooperative Community-based Perinatal Studies and Interventions in Minority Populations; the Toxicity of Lead in Children Clinical Trial; Minority Youth Health Behavior Research: The Development and Evaluation of Interventions; the Genetic Basis of Diabetes in Minority Populations Study; and the Exploratory Center Grants for Research on Health Promotion and Disease Prevention in Older Minority Populations.

New initiatives in minority research training that have been launched as part of the MHI include: the Bridges to the Future Program; the Minority International Research Training Program; and the NIH/National Science Foundation (NSF) Memorandum of Agreement.

### *Minority Health Research*

The **Infant Mortality** component of the MHI supports community-based epidemiological and clinical research to address the problem of the unacceptably high infant mortality rate in Washington, DC. Despite overall



improvements in national infant mortality rates, African American infants continue to be twice as likely as white infants to die within the first year of life. This problem can clearly be seen in the District of Columbia, a predominantly African American city that has the Nation's highest infant mortality rate.

The **Minority Children** component focuses on research on injury-related morbidity, lead poisoning, asthma, learning disorders, and hearing and speech impairments among minority children ages 1-9. This component includes a major research initiative to address the etiology and treatment of a variety of environmental-related health problems in minority children.

The **Minority Youth Initiative** focuses on evaluating and comparing various community-based interventions to decrease violence-related injuries and deaths, sexually transmitted diseases (STDs), and unintended pregnancies in minority youths ages 10-24. Minority youths are at greater risk for suicide, homicide, substance abuse, unintended pregnancy, and STDs, including AIDS. Homicide is the leading cause of death for minority youth; the rate of death by homicide is almost ten times higher for African American youths than for white youths. This initiative also supports a comprehensive community-based program to include minority adolescents with HIV in clinical studies of novel HIV treatments.

The **Young Adult Initiative** supports a variety of research projects, both intramural and extramural, related to the health problems and behaviors of young minority adults. Research projects focus on health problems such as kidney disease, hypertension, diabetes, obesity, glaucoma, hemochromatosis, lupus, alcoholism, and AIDS, all of which are conditions known to inordinately affect the minority community. Studies to examine the recruitment and compliance of minorities in clinical trials are also supported.

The **Older Minority Americans** component of the MHI funds research centers dedicated to the study of diseases



and conditions that lead to ill health and disability in aging minority populations. Six centers are currently studying such conditions as hypertension, cancer, diabetes, and arthritis.

### ***Minority Biomedical Research Training***

The **Bridges to the Future Program** provides linkages for minority students (1) between two-year junior or community colleges and four-year colleges, and (2) between terminal M.S. degree programs and Ph.D. programs. These have been identified as two key drop-out points for students considering research careers. The Bridges Program also fosters relationships between M.S. degree-granting minority institutions and research-intensive Ph.D.-granting institutions.

The **Minority International Research Training Program** supports international research and research training of undergraduate, graduate, and postgraduate minority students, as well as minority faculty. MIRT grants are awarded to colleges and universities that independently select students and faculty members to conduct scientific research at foreign universities or research centers. International study programs are known to be important in preparing the next generation of scientific leaders to work effectively in a global environment. However, minority students are less likely than their nonminority counterparts to develop contacts that facilitate participation in study-abroad programs.

Through the MHI, the **NIH/NSF Memorandum of Agreement** was initiated. This agreement provides for a collaboration between the ORMH and the NSF on three projects previously established by the NSF:

Comprehensive Regional Centers for Minorities (CRCM);  
Partnerships for Minority Student Achievement (PMSA);  
and Alliances for Minority Student Participation (AMP).



The ORMH is working with the NSF to expand and emphasize the biomedical components of these middle school, high school, and college science programs.

The MHI provides **supplementary funding for existing minority training programs** sponsored by the NIH ICDs. These programs include: Minority Biomedical Research Support, Minority Access to Research Careers, Research Centers in Minority Institutions, and the Minority High School Student Research Apprentice Program. The MHI also provides support for the Research Supplements for Underrepresented Minorities Program and the Public Health Service's Historically Black Colleges and Universities Capacity-Building Demonstration Project.

### *Additional ORMH Activities*

In addition to providing administrative support for the MHI, the ORMH supports technical assistance workshops; a contract effort to develop a strategy to educate minorities about organ and tissue donation; a comprehensive, ongoing evaluation of NIH minority programs; and other outreach and liaison activities.

The ORMH is expanding its efforts to assist minority investigators interested in applying for NIH grants by sponsoring technical assistance workshops with the NIH grant-awarding ICDs. These workshops are designed to increase the grant-writing capability of investigators at minority institutions and thus increase their success in applying for NIH grants. So that the success of this effort can be tracked, the ORMH requires that these workshops address a specific Request for Applications (RFA) or Program Announcement (PA). The ORMH, in collaboration with the sponsoring Institute or Center, will collect data on the number of workshop participants who submit grant applications, as well as on the success of those applications.

Minority Americans are disproportionately affected by many diseases and conditions, including renal and kidney diseases, liver dysfunction, and cardiovascular disease.



Morbidity and mortality from these diseases may be improved by organ or tissue transplants. However, Gallup Survey results reveal that only 11 percent of African Americans are "very willing" to donate their organs, compared with about one-third of white Americans. Therefore, the ORMH has awarded a contract to develop a strategic plan to educate minority Americans about the importance of organ donation. At the heart of this educational strategy is the use of community resources such as civic leaders, educational institutions, community and health care organizations, and the media. This strategy is being implemented in 11 cities nationwide and will involve all principal minority groups (Native Americans, Asian/Pacific Islander Americans, Hispanic Americans, and African Americans).

The Minority Programs Evaluation Committee, convened in 1992 by the Director of the ORMH, has begun an assessment of all NIH training and education programs targeted to minorities. In June of 1993, the ORMH released *Assessment of NIH Minority Research/ Training Programs: Phase 1*, a report that presents available information and trend data on NIH minority research training programs. The second phase of the project, to be completed in FY 1995, involves a feasibility study to design a prospective assessment and tracking system. The third phase, to be completed in FY 1996, will involve implementation of the assessment and tracking system.

A substantial portion of the ORMH budget supports outreach activities, including collaborative efforts with the ICDs. The ORMH continues to educate the minority community about important NIH policies and programs, including the NIH guidelines on the inclusion of women and minorities in research. ORMH staff regularly attend meetings and conferences to provide information on NIH minority research and research training initiatives. To facilitate dialogue with constituencies, the ORMH sponsors town meetings, workshops, and regional conferences such as the 1991 regional conferences and the Chicago Conference.



## ***THE CHICAGO CONFERENCE: PURPOSE AND SCOPE***

Policy-making through consultation is an ongoing process. Once policies have been implemented, there is a need to evaluate them, obtain feedback on their effectiveness, and continue dialogue with grassroots constituencies. The ORMH is committed to ongoing review of its programs, recognizing that needs change and that programs which are appropriate in one set of circumstances may no longer be appropriate as those circumstances evolve. Thus, in 1994—four years after the establishment of the ORMH and three years after the 1991 regional conferences that resulted in the Fact-Finding Team report—the time was right for a further round of consultation.

The National Conference on Minority Health Research and Research Training took place in Chicago, Illinois, from March 27-30, 1994. The conference had the following goals: (1) to inform the various ORMH constituencies of the progress made in responding to the recommendations of the 1991 Fact-Finding Team; (2) to solicit feedback on those achievements; and (3) to obtain further information on the needs of minority populations in order to design responsive new ORMH programs for the years 1995-2000.

The three 1991 regional meetings at which the ORMH consultative policy-making process was first employed were held in the East, South, and West of the country. As the ORMH began to plan its fourth major conference, minority health researchers, practitioners, and academicians from the Midwest voiced concern that their input was not adequately incorporated into the 1991 Fact-Finding Team recommendations. To ensure adequate representation of Midwesterners in this review of ORMH activities, the Office held the Conference in Chicago and made a concerted effort to identify concerned and knowledgeable individuals from the Midwest region. As a result of these efforts, over 50 percent of the 350 Conference participants



were from the Midwest. Mindful of the need to achieve national representation among the Conference attendees, the ORMH also invited all participants in the 1991 regional meetings to attend the Chicago Conference.

As in 1991, an expert panel was appointed to write a report and make recommendations based on the conference deliberations. This 43-member panel, known as the Assessment Team (**Appendix II**), included more than half of the members of the 1991 Fact-Finding Team. This continuity provided both experience with the process and a familiarity with the issues, while new members of the Assessment Team brought a fresh perspective to the task of evaluating the accomplishments and future direction of the ORMH and of NIH minority health and research training programs. Assessment Team members aided the ORMH by setting the agenda for the Conference, identifying participants, and moderating breakout sessions.

They also produced a new set of recommendations to add to those of the Fact-Finding Team. These recommendations will guide the ORMH into the 21st century.

Much of the Conference was structured around the goal of providing participants with the opportunity to learn about ORMH programs and to voice their reactions to what they had learned. Throughout the Conference there were efforts to ensure community involvement in the proceedings. As part of that effort, the Conference was co-chaired by Dr. Norman Francis, President of Xavier University of Louisiana, and Dr. Candida Acosta, President of the University of Phoenix in Puerto Rico.

The Conference began on March 27 with an evening orientation session and reception, including a videotaped welcome from Dr. Donna Shalala, Secretary of the Department of Health and Human Services and a member of the 1991 Fact-Finding Team. Dr. Shalala applauded the efforts of the ORMH and encouraged the participants to take seriously the opportunity to make additional recommendations and suggestions to the NIH.



March 28, the first full day of the Conference, was initiated by Dr. Harold Varmus, Director of the NIH. His address on the inclusion of minorities in clinical research set the stage for a day-long series of presentations on 20 ORMH-supported programs. These presentations were made by Institute directors, intramural researchers, extramural grantees, and NIH program administrators. (Abstracts of these presentations are attached as **Appendix III**). These presentations provided useful information on ORMH-sponsored programs and the relationship of these programs to the Fact-Finding Team's recommendations. They clearly demonstrated that the ORMH had been active in sponsoring minority health research and research training programs across the NIH. Lunch and dinner speakers during the first day were, respectively, U.S. Representatives Louis Stokes of Ohio and Cardiss Collins of Illinois, both of whom spoke about their commitment to minority health research and research training.

ORMH Director Dr. John Ruffin opened the second day of the Conference with a speech emphasizing the importance of acting in partnership to successfully overcome the health and training problems of minority Americans. Following his speech, Conference participants met in small discussion groups. While the first day of the Conference had focused on providing participants with information about ORMH initiatives, the second day was devoted to collecting feedback and recommendations from attendees. In the morning, participants voiced their opinions on minority health issues; in the afternoon, they addressed minority research training issues. Each breakout session had two moderators, an Assessment Team member and an NIH representative, who were responsible for summarizing the group's discussions and presenting a brief report to the plenary session that followed each breakout. During lunch, U.S. Representative Luis Gutierrez of Illinois spoke to the participants about his commitment to enhancing minority health through improvements in research and health care delivery.



Assessment Team members remained in Chicago for an additional day of work in which they began to reach consensus on the priorities expressed by the community. The Team appointed a Writing Group to produce a conference report that included recommendations for action.

The Writing Group met in Atlanta, Georgia, on July 6-7, 1994, to complete its report.



## ***CONFERENCE OUTCOMES***

### ***Consensus of the Minority Biomedical Community: Results of Conference Evaluation***

As part of the activities of the Chicago Conference, the ORMH prepared and widely distributed a Conference evaluation questionnaire that solicited participants' opinions about the current work of the ORMH. Many individuals completed the questionnaire at the Conference, while others took it home and polled their colleagues before returning it. Therefore, the feedback received represents more than the opinions of the 170 individuals who completed and returned their evaluation forms to the ORMH. The results of the evaluation are summarized in **Table 1**.

The consensus of the participants, as expressed in their responses to the Conference evaluation questionnaire, was: (1) that ORMH personnel have been open and receptive to input from the community; (2) that the ORMH has made good progress in generating programs responsive to the original 13 FFT recommendations for minority health research and research training; and (3) that the ORMH has increased the awareness of minority concerns at all levels of the NIH. The participants agreed that the ORMH should continue to encourage the ICDs to fund more minority research and to collaborate with other government agencies to leverage funds for more minority programs. Over 75 percent of participants felt that the ORMH is achieving its dual goals of increasing research on diseases that disproportionately affect minority groups and involving more minorities in biomedical research.

### ***Assessment Team Identification of Priorities and Recommendations***

A subgroup of the Assessment Team, the Writing Group, met in Atlanta, Georgia, on July 6-7, 1994, to distill from the Conference proceedings a set of recommendations to guide ORMH activities for the years 1995-2000. To generate its recommendations, the Team summarized breakout session transcripts, session reports, and discussions in general sessions. The team concluded that, overall, the community had: (1) expressed its satisfaction with the current efforts of ORMH to meet its dual goals of improving minority



health and increasing the participation of minorities in biomedical research; and (2) encouraged the ORMH and the NIH to continue to fulfill the original 13 Fact-Finding Team recommendations and to look carefully at new areas of concern and interest to the minority biomedical community.

Discussions at the Conference highlighted **six priority areas** that the community felt should shape the ORMH's efforts during the second half of the 1990s.

### *ORMH Priorities Identified by the Community*

#### ***1. Inclusion of Minorities in Biomedical Research Populations***

In the past, some research studies that included minorities were of poor scientific quality and involved abuse or mistreatment of participants. These unfortunate experiences, along with economic disadvantage and other factors, have combined to make many minority individuals reluctant to take part in clinical research. Therefore, while there is a need to include more minorities in research study populations in order to answer important scientific questions, there is also a need to design studies with sensitivity to overcome the reluctance of many minority individuals to participate in clinical research.

The Assessment Team asks that the ORMH make it a priority to work with the Institutes, Centers, and Divisions of NIH, as well as with other Public Health Service agencies and minority communities, in order to: (1) demonstrate to biomedical researchers that (a) including minorities in studies will improve results and (b) minority subjects can be recruited to participate in biomedical studies; (2) demonstrate to minority groups the value of participating in biomedical studies; and (3) facilitate communications among researchers and minority community health organizations.



## ***2. Collaborative Research Programs Between Majority and Minority Institutions***

The concept of institutional role modeling is a very important mechanism in enabling the ORMH to reach its goals of improving minority health and increasing the participation of minorities in biomedical research. The idea of institutional role modeling has its roots in the concept of mentoring, which is a well-established mechanism for individual professional development. Applying the concept to institutions creates a situation with unique benefits for both the minority and majority partner institutions. The minority institution obtains access to NIH funding and expertise as well as to the resources and facilities of the majority institution. This results in better recruitment and retention of faculty, more opportunities for students, and an opportunity to develop institutional expertise in research administration. The majority institution is able to broaden the scope of its mission, heighten the diversity of its activities, and reshape its future as an institution.

ORMH is already supporting several minority-majority collaborative research programs. Discussions at the Chicago Conference indicated that the community strongly supports these efforts and desires to see them expanded. Therefore, the Assessment Team asks ORMH to make it a priority to strengthen and expand these activities with the aim of creating minority research institutions that serve as role models for other minority institutions.

## ***3. Expansion of Research Training Opportunities for Health Care Professionals***

Well-established NIH research training programs such as the Minority Access to Research Careers (MARC) Predoctoral Fellowship Program and the National Minority Predoctoral Fellowship provide opportunities for minority students pursuing Ph.D.s in the biomedical sciences.



However, many minority undergraduate students who receive support through the MARC, Minority Biomedical Research Support (MBRS), and other programs go on to obtain professional degrees in medicine, dentistry, and veterinary medicine. There is a need for research support programs that would enable these professionally trained individuals to gain advanced research training and enter full- or part-time careers in biomedical research. The Assessment Team asks ORMH to make it a priority to set up such a program on a pilot basis.

#### ***4. Increasing Utilization of NIH Minority Research Supplements***

The NIH Minority Research Supplements program enables principal investigators (PIs) holding NIH research grants to apply for supplements to support underrepresented minorities who wish to gain research experience by working in the PI's laboratory. The program provides opportunities for individuals from underrepresented minority groups at any career level (from high school to university faculty) to pursue a research experience in a research-intensive environment anywhere in the United States. This program helps to develop minority researchers who can go on to successfully apply for investigator-initiated research grants (R01 awards). The Assessment Team asks the ORMH to strengthen and expand its support of the research supplements program with the aim of increasing both the number of minorities entering careers in biomedical research and the number of minority researchers who successfully apply for NIH investigator-initiated research grants.

#### ***5. Increasing the Competitiveness of Minority Researchers***

The minority community supports the efforts that ORMH has made to strengthen the competitive position of minority researchers applying for NIH grants by providing



financial support to NIH Institutes and Centers for technical assistance workshops on the grant application process. These workshops are open to all potential NIH grantees. ORMH sponsors minority researchers who wish to attend these workshops. Individuals who have attended these workshops have subsequently been successful in obtaining independent NIH research grants. The Assessment Team asks the ORMH to strengthen and expand these activities with the aim of increasing the number of minority researchers who successfully apply for NIH research support.

#### ***6. Development of a Coordinated Research/Training Information System***

The Assessment Team asks the ORMH to develop a coordinated information system to link the various NIH minority research/training programs and similar programs sponsored by other organizations. The system should be designed to: (1) help students, faculty, and program administrators become more aware of the scientific research/training opportunities available to minority individuals; (2) track the progress of minority individuals in their pursuit of careers in biomedical or behavioral research; (3) provide information useful in assessing minority research/training programs and identifying factors related to success; and (4) increase the number of minority individuals who pursue careers in biomedical and behavioral research.

#### ***Recommendations from the Community for New and Expanded Activities***

Recommendations for new areas of emphasis for ORMH programs in both research and training, based on the community's deliberations at the Chicago conference, fall into four major areas:

- ◆ Minority Health Research
- ◆ Minority Research Training
- ◆ Outreach
- ◆ The Role of the ORMH



## MINORITY HEALTH RESEARCH

The following recommendations relate to Priority Area 1 outlined above, the inclusion of minorities in research study populations.

### I

**The Assessment Team recommends that the NIH support and conduct biomedical and biobehavioral research on the varied health problems of each of the four minority groups, as well as their many subgroups.**

The Assessment Team urges that the NIH initiate research in the following areas:

- ◆ *Research on the effects of migration on health, focusing on migration to as well as within the United States.* Much of the growth in the minority population is a result of migration to the United States. This is an appropriate subject for NIH-supported research because changes in living conditions, diet, and socioeconomic status as a result of migration can impact health status. With regard to internal migration, the Assessment Team is concerned that not enough is known about the health status of migrant workers, the vast majority of whom are of Hispanic descent. Because of the difficulties of conducting research on such a transient population, the NIH should collaborate with the community-based organizations that provide health services to these workers.
- ◆ *Research on the effects of environment on health status.* The Assessment Team commends the ORMH and the National Institute of Environmental Health Sciences for their joint commitment to research on the health and behavioral effects of childhood lead exposure in innercity neighborhoods. The Assessment Team recommends that this collaboration be extended to additional health conditions and locations, particularly the U.S.-Mexico border region.



- ◆ *Research on the health of minority women.* The Assessment Team is concerned about a variety of women's health issues, including reproductive health, mental health during pregnancy and the effects of poor mental health on both mother and child, and the health of post-menopausal women. The Assessment Team recommends that the ORMH and the NIH Office of Research on Women's Health collaborate on a minority women's health initiative.

## II

**The ORMH should coordinate and facilitate a strong minority health initiative in behavioral, social, and sociocultural research. Such an initiative should include basic research, prevention, and intervention in such health areas as nutrition, mental health, and substance abuse.**

The ORMH already has initiated several programs that address health behaviors, including the Minority Youth Health Behavior Initiative and the Long-Term Outcome of Obesity Treatment in Minority Women study. The Assessment Team recommends that additional behavioral research initiatives be undertaken and urges the ORMH to collaborate with the newly established NIH Office of Behavioral and Social Science Research. Expanded research in the behavioral and social sciences is particularly timely given the recent addition of the National Institute on Alcohol Abuse and Alcoholism, the National Institute on Drug Abuse, and the National Institute of Mental Health to the NIH.

## III

**The Assessment Team recommends that the NIH expand its collaborative research activities on minority health.**

While the NIH is the focal point for federally funded biomedical and behavioral research, other federal agencies



also support and conduct research. The NIH, through the leadership of the ORMH, should develop memoranda of understanding with the Departments of Agriculture, Energy, and Defense, as well as with the National Aeronautics and Space Administration and the National Science Foundation. Such collaborative research arrangements would stimulate minority health research across Federal government agencies. The Assessment Team also recommends that the NIH work more closely with service-providing agencies such as the Centers for Disease Control and Prevention, State Departments of Health, and State Offices of Minority Health. These agencies can continue to provide much-needed care to underserved populations after the NIH completes its clinical research.

## IV

**The NIH should make greater efforts to involve community-based organizations in its minority health research projects.**

Community-based organizations can contribute to the research enterprise, especially in the area of recruitment for clinical research. Because of their ties to the minority community, community-based organizations (CBOs) can develop outreach campaigns to overcome the reluctance of minorities to participate in clinical trials. With the assistance of the NIH, the Assessment Team believes that some CBOs could successfully compete for NIH grants. The Assessment Team recommends that NIH sponsor workshops to assist CBOs in identifying research questions, initiating partnerships with research organizations, and developing research proposals. Once research projects are underway, the NIH should carefully monitor partnerships between CBOs and research organizations to ensure that the CBOs are active research partners.



## **MINORITY RESEARCH TRAINING**

The following recommendations relate to Priority Area 2, collaborative research programs between majority and minority institutions; Priority Area 3, expansion of research training opportunities for health care professionals; Priority Area 4, increasing the utilization of NIH minority research supplements, and Priority Area 5, increasing the competitiveness of minority researchers.

### **V**

**The Assessment Team urges that, consistent with recommendation XII of the Fact-Finding Team, the NIH expand its activities to support academic institutions with 50 percent or greater enrollment of underrepresented minorities.**

**The NIH should recognize the need to enhance both the quality of teaching and training provided to students and the research environment and professional capabilities of the faculty at these institutions.**

The NIH should seek new ways to improve learning opportunities for students at predominantly minority institutions by supporting continuing education for faculty at these institutions through assistance in the completion of terminal degrees, partial leave support, summer research and training, educational travel, awards for outstanding performance, etc. In addition, funding should be made available for junior faculty to initiate research activities.

### **VI**

**The NIH should make funds available to fully develop the infrastructure of institutions with 50 percent or greater enrollment of underrepresented minorities.**

Infrastructure support should be available to institutions with undergraduate and/or graduate programs. The Research Centers in Minority Institutions (RCMI) program has done much to improve the research capacity of many



doctoral degree-granting minority institutions. However, many other minority institutions, particularly those not offering the doctoral degree, are in need of infrastructure development. Therefore, the Assessment Team recommends that the RCMI program be expanded to institutions offering the master's degree and eventually to institutions offering the bachelor's degree.

As appropriate, the NIH should support the development of Centers of Excellence at those minority institutions that are long-time beneficiaries of NIH infrastructure support. These institutions are poised to serve as regional centers for the training of minorities and for the conduct of minority health research.

Minority institutions should be encouraged to form consortia to utilize resources more efficiently. Smaller 4-year institutions and community colleges have much to gain from organizing regional consortia, and they should be encouraged to utilize these consortia as they compete for grants and recruit students for their training programs.

## VII

**The ORMH should initiate and provide partial financial support for research/training partnerships based at minority institutions. Such partnerships should require cost-sharing from affiliated industries, other government agencies, majority institutions, and/or national laboratories.**

Most minority institutions are inadequately prepared to train prospective scientists without human and physical resource supplementation. In an effort to alleviate this dilemma, the Assessment Team strongly recommends that the ORMH initiate new research/training partnership programs. Significant cost-sharing could be effectively and efficiently used to defray the expense of infrastructure development (instrumentation, facilities construction, etc.). The expected outcome will be an increased number of trained personnel for industry, science education, and biomedical research.



The Assessment Team also recognizes the important contribution that minority institutions can make to ongoing research efforts at majority institutions. Most notably, minority institutions are well situated to recruit patient cohorts for clinical trials and to assist with the retention of minority participants. The Research Supplements for Minority Investigators program and other similar programs allow scientists at minority institutions to learn from and contribute to the research conducted by scientists at majority institutions. However, the NIH should also establish grant mechanisms that would require this type of collaboration and provide opportunities for minority institutions to serve as the lead institutions in collaborative research studies.

## VIII

**The Assessment Team encourages the NIH to continue to fund its current training programs, and to expand those efforts as follows:**

- ◆ *Expansion of the Bridges to the Future Program.* The Assessment Team is pleased with the speed with which the ORMH, in collaboration with the National Institute of General Medical Sciences, developed and implemented the Bridges to the Future Program. A mechanism now exists to assist students at community colleges and in terminal master's degree programs in progressing to the next level of educational attainment. Although these are critical stages for bridging, they are not the only times when minorities are lost from the educational pipeline. The Assessment Team recommends expanding the bridging concept to develop links between high schools and two-year and four-year colleges; four-year colleges and graduate schools; and four-year colleges and medical schools.
- ◆ *Initiation of a research apprenticeship program for minority undergraduates.* The Minority High School Student Research Apprenticeship Program provides



hands-on research experience to high school students and teachers. A similar program should be developed to provide substantive summer research opportunities to undergraduate minority students.

- ◆ *Expansion and promotion of the Research Supplements for Underrepresented Minorities program.* The program should be better advertised and stronger incentives should be developed to encourage PIs to apply for supplements to their grants. Recognizing the utility of this program, the Assessment Team recommends that it be extended to minority high school science teachers from predominantly minority school districts.
- ◆ *Initiation of a combined MARC/ MBRS pilot program.* Several institutions that receive funding for both the MARC and MBRS programs should be selected as sites for a pilot program that would seek to determine if this combined approach would generate cost savings and decrease review time.
- ◆ *Addition of a second track to the MARC program.* The MARC Program should have two training tracks, one for students interested in pursuing the Ph.D. and one for students interested in pursuing the M.D.
- ◆ *Expansion of the Minority Dissertation Research Grants in Aging program.* This program, which assists minority graduate students in the completion of Ph.D. degrees, should be expanded to other institutes and research areas.

## IX

**The NIH should initiate training activities that respond to the needs of minorities at every stage of their educational or professional development. The Assessment Team recommends that the NIH place increased emphasis on the following areas:**

- ◆ *Focus on the early stages of education by implementing innovative programs to interest younger*



*students in science.* Program suggestions include mobile science labs that deliver predesigned experiments to schools and residential summer research experiences that continue for two or more consecutive summers.

- ◆ *Provide assistance to institutions for the development of orientation, mentoring, and retention programs for underrepresented ethnic minorities in the biomedical area.* Support should include funds for faculty release, peer tutoring, and mentoring.
- ◆ *Support programs for minority students and faculty at majority institutions.* These institutions must take responsibility for the recruitment and retention of minority students.
- ◆ *Provide research opportunities for minority students who decide to pursue an M.D. rather than a Ph.D.* Many minority students, including those who have participated in the MARC and MBRS programs, opt for M.D. rather than Ph.D. programs. To interest these students in research, the NIH should provide hands-on research experience between the first and second years of medical school.
- ◆ *Support visiting scientists programs that would encourage faculty from majority institutions to conduct research at minority institutions* and enable scientists from minority institutions to conduct research at major research institutions, including the NIH.
- ◆ *Provide support for research training in public and allied health.* Involve Schools of Public Health in minority health research and increase the emphasis on research training of nurses and other allied health professionals.



- ◆ *Establish a new research grant mechanism* that would emphasize training through active participation in research to take advantage of the training and mentoring skills of certain researchers. In effect, the research would serve as the vehicle for training.
- ◆ *Provide training opportunities* to minorities with B.S. and M.S. science degrees who are currently employed by Federal agencies, including the NIH.

## OUTREACH

The following recommendations relate to Priority Area 6, development of a coordinated research/training information system.

### X

**The ORMH should be responsible for disseminating information regarding NIH minority health research and minority training programs.**

Specific suggestions for how such information dissemination might be achieved include:

- ◆ *Collection of data from minority health research projects.* A central repository of data from minority health research should be made available to all health practitioners. The repository could be established using the National Library of Medicine system.
- ◆ *A minority health research hotline and/or electronic bulletin board.* Information should be made available to researchers on current Requests for Applications on minority health issues, deadlines for application submission, and review and award dates. Those accessing the hotline or bulletin board should be able to request application packets. A system should be in place to respond promptly to these requests.



- ◆ *Regional ethnic group meetings.* Information on minority health and training should be disseminated to targeted ethnic minority groups at annual regional meetings organized by ORMH.
- ◆ *National conference on minority health.* A broad-based conference to update all ethnic minority groups on health and training issues should be held every four years.
- ◆ *Publications on minority health and training issues.* The ORMH should generate publications to inform science teachers (through their associations) of minority health issues, biomedical issues, and research opportunities. The ORMH should also provide user-friendly information for K-12 students regarding biomedical career options.

In addition, the ORMH should make efforts to include information on minority health and training issues in *The Journal of NIH Research*.

## XI

**The ORMH should develop a database listing the research interests and capabilities of minority scientists, minority institutions, and community-based organizations.**

This database should be made available to NIH ICDs, other government agencies, and private research foundations. The ORMH should encourage the Institutes to use this database to increase minority representation on study sections and review panels and to select minority scientists and representatives from minority institutions and community-based organizations to observe the deliberations of study sections and/or review panels.



## THE ROLE OF THE ORMH

### XII

**The ORMH should function as a central leadership entity at the NIH for issues related to minority health research and research training.**

To reduce duplication of effort, spearhead new initiatives, and ensure the general and timely dissemination of research results to the minority community, the ORMH should coordinate, review and advocate for all NIH programs for underrepresented minorities. The ORMH should also serve as a focal point for informing minorities about, and motivating them to participate in, NIH-sponsored clinical trials. In addition, the ORMH should seek to strengthen the language regarding minority participation in research involving human subjects. As the trans-NIH office for minority health research and research training, the ORMH must set priorities and engage in trans-NIH long-term planning.

The Assessment Team recommends that the ORMH define clear minority health research priorities for the NIH, similar to those set forth by the Public Health Service in Healthy People 2000. These priorities, which should focus on the health problems that contribute most to morbidity and mortality in minorities, must encompass all racial and ethnic groups. The ORMH should continue to consult with the minority community as it develops its list of minority health research priorities.

The Assessment Team urges the ORMH to continue to provide initial financial support for new minority programs. However, it is essential that the NIH ICDs assume financial responsibility for programs that demonstrate effectiveness following an initial period of ORMH support. The funds thus released should then be used by the ORMH to initiate new programs.



### **XIII**

**The Assessment Team supports the involvement of the minority community in a formal advisory role to the ORMH.**

The Assessment Team strongly supports the appointment of an External Advisory Committee (EAC) to provide counsel and advice to the Director of the ORMH. This committee should be appointed by the Director and should include broad representation from all underrepresented minority groups. The EAC should meet at least twice a year to review the ORMH's programmatic initiatives and advise the Director on budgetary priorities; research and training initiatives that merit support; and assessment and evaluation of NIH minority programs.



**TABLE 1**  
**Summary of Conference Evaluations**  
**NATIONAL CONFERENCE ON**  
**MINORITY HEALTH RESEARCH AND RESEARCH TRAINING**  
**March 27-30, 1994**

<i>Raw Numbers of Responses</i>					
1	2	3	4	5	
Strong Agreement				Strong Disagreement	
95	53	13	3	1	The ORMH has made progress in generating new programs to address minority health research concerns.
74	66	18	4	1	The ORMH has made progress in generating new programs to address minority biomedical training concerns.
80	57	14	2	2	ORMH has effectively used the recommendations from the 1991 FFT meeting in program planning.
56	72	29	3	2	ORMH has been successful in substantially encouraging the Institutes in addressing and funding of minority issues at NIH.
55	59	34	3	13	ORMH has worked well with other government agencies to leverage NIH funds for minority programs.
69	69	15	6	3	ORMH has increased the awareness of minority concerns at all levels of NIH.
94	45	14	3	10	ORMH is open and receptive to input from all segments of the minority biomedical communities.
70	65	25	6	0	I think the dollars being spent on minority programs and issues at NIH are being well used.
57	57	26	6	0	ORMH is achieving its dual goal of significantly increasing research on diseases afflicting minority groups and involving more minorities in biomedical research.
102	34	11	2	4	ORMH personnel have been informative and helpful when I have approached them with questions and suggestions.
125	30	8	5	2	This Chicago Conference has been of value and afforded the opportunity for further input and strengthening of the NIH Programs for minorities.
*Total of 170 responses					



## **APPENDIX I**

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### **RECOMMENDATIONS OF 1991 FACT-FINDING TEAM**







## *Introduction*

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In May 1991, the National Institutes of Health Office of Minority Programs (OMP) formed an advisory Fact-Finding Team (FFT) to recommend ways by which NIH could (1) help extend healthy life and reduce the burden of illness among minorities through targeted research and (2) significantly increase the participation of minorities in all phases of biomedical research.

The 53-person team was co-chaired by Dr. David Satcher, President of Meharry Medical College, Nashville, Tennessee, and Dr. Norman C. Francis, President of Xavier University, New Orleans, Louisiana.\* Between May and September, the FFT attended three major regional meetings convened by the OMP in Arlington, Virginia; Atlanta, Georgia, and San Diego, California. At these meetings, FFT members gathered information and ideas from the nearly 1,000 participants who represented a broad spectrum of educational, government, and community organizations and the biomedical and life sciences communities.

Following the San Diego regional meeting, the FFT drafted its recommendations and submitted them to the Associate Director of NIH for Minority Programs. He, in turn, will submit them to the Advisory Committee to the Director of NIH as guidance for future policy deliberations in regard to support for minority programs and research initiatives at the National Institutes of Health. The report also serves as an invaluable guide for the continued evolution of the OMP itself.

This report focuses on the health needs of minority Americans—encompassing groups which, by their numbers, represent a smaller proportion of all Americans than white Americans. Minority Americans are traditionally underserved in the health care system and traditionally underrepresented among health care providers. Within the four groups identified as "minority" Americans in this report—African Americans, Hispanic Americans, American Indians and Asian Americans—there is great variability of health problems. For example, not all minority groups have the same rates of infant mortality or hypertension. Readers are cautioned not to draw conclusions about the health problems of each minority group based on statements that focus on the health problems of "minorities." The Fact-Finding Team is sensitive to this distinction and its recommended program priorities reflect an awareness of the particular differences between minority groups.

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\*A complete list of members is included at the conclusion of this report.







## RECOMMENDATIONS

### I-IV

#### Life Span and Disease Conditions

The FFT noted that, while every American hopes to enjoy a long, happy and productive life, minority Americans (i.e., African Americans, Hispanics, American Indians and Alaska Natives, and Asians and Pacific Islanders) suffer a disproportionate burden of illness and death compared to the predominantly white majority. For example, the Report of the Secretary's Task Force on Black and Minority Health, published in 1985 by the Department of Health and Human Services (HHS), indicated that this disparity was on the order of 60,000 "excess deaths" each year among Blacks, compared to mortality rates among the country's majority population.

The report also indicated that the primary causes of these excess deaths were the following six major health problems

- heart disease, stroke and hypertension
- homicide and preventable accidents
- cancers
- infant mortality and perinatal morbidity
- cirrhosis and liver failure
- diabetes

In 1990, HHS published *Healthy People 2000*, an overview of the current and projected health status of Americans. Again, the disparities between majority and minority Americans were evident, and the same six categories of health problems were identified as the primary causes for the disparities. In addition, the disproportionate impact of the AIDS epidemic on minority populations was becoming apparent. Now it is known that AIDS is among the leading causes of death among African Americans and Hispanic Americans.

The following FFT recommendations reflect the information in the two previously mentioned reports as well as a profound concern regarding the six categories of health problems. The recommendations specifically address the issues of shorter life span and of the higher incidence of certain disease conditions among America's minorities. For some recommendations, new funding is required and should be sought by NIH. For many recommendations, new funding is not required; rather, a shift in program emphasis or focus within NIH and throughout the institutions supported with NIH grants will be sufficient to address the concerns.

#### I

**NIH should urgently provide clear goals and adequate funding for research to extend healthy life and to reduce the burden of illness among minority populations to be equivalent to that of the general population by the year 2000.**

The FFT recommended that research programs be focused in three key areas: Life-Span Issues, Chronic Diseases and Infectious Diseases.

*A. Life-Span Issues related to extending the lives of minorities and lowering morbidity throughout the lifespan include prenatal and infant concerns, childhood and adolescent concerns, and adult concerns up through the elder years.*

Minorities face increased risks from the beginning of life when the rates of low birthweight and infant mortality are elevated. Improving life-span must begin with addressing general problems such as lack of prenatal care



and low birthweight and also specific health problems, such as fetal alcohol syndrome, fetal drug addiction and sudden death syndrome. Concern about the early years of life must also include the well being of mothers and issues related to maternal mortality and reproductive health.

While childhood is a generally healthy period of life, there are threats to well-being that challenge minority health. The problem of lead poisoning is reflective of the need to understand interrelationships of medical problems with the social and economic environment in which many minorities live. Other problems involve iron deficiency anemia, dental caries, child abuse, trauma and unintentional injury. Adolescence provides new challenges as children move into adulthood and face a new set of risks to health. Early childbearing and sexually transmitted diseases become issues of concern. Increasingly, the health of adolescents is beset by concerns such as violence and homicide, which have only recently been embraced by the health establishment. Substance abuse and suicide reflect not only risks to health and life, but may be indicators of the stress of the transition to adulthood. Mental health, alcohol abuse and substance abuse issues require particular attention when dealing with adolescent concerns.

Adult concerns such as smoking, smokeless tobacco and alcohol demonstrate the relationship between lifestyle and health. These major risks to later disease must be addressed early with a goal of a healthier lifestyle and longer life. Unfortunately, problems of homicide, suicide and unintentional injury continue into adulthood. Ethnically-related infertility becomes a problem in adulthood and one related to earlier risks to reproductive health. Concerns of the elderly include nutrition, inactivity, pharmacology and pharmacokinetics. Because men tend to die at a younger

age than women, the problems of the elderly are also often the problems of women. Again, the interface of health with social and economic well-being must be considered.

#### **B. Chronic Diseases with high incidence among minorities.**

Among these are coronary heart disease, high blood pressure and stroke, asthma, cancer (especially breast, lung, and liver cancer), renal disease, diabetes (and the relationship of obesity to diabetes), and alcohol-related diseases such as cirrhosis.

#### **C. Infectious Diseases with a high incidence among certain minority groups.**

These would include sexually transmitted diseases, viral hepatitis, tuberculosis, and bacterial meningitis. The escalating impact of AIDS on minority populations also requires immediate and urgent attention.

## **II**

The FFT recommends that the NIH undertake additional longitudinal and data collection studies among the many diverse population groups referred to as "minority groups" in order to better determine those factors that affect the health status and needs of minorities.

The FFT noted that current data bases concentrate on African American statistics, with some information on Hispanics. The regional representatives and the FFT members emphasized in their discussions that minorities in the U.S. are extremely diverse and that insufficient data exist for many groups. For example, some as yet unidentified health problems may be devastating certain small ethnic groups. These conditions remain unknown because these population sub-sets are aggregated into a larger single minority data base. It is clear that various Indian tribes have health



concerns that are different, one from the other; that the term "Hispanic" subsumes a great diversity of peoples and cultures of North, Central and South America; and that "Asian" population groups are as heterogeneous as "Caucasian" populations. Therefore, all studies must assure inclusion of sufficient numbers of these minority groups to permit clear inferences.

The FFT strongly recommends that OMP take the lead in efforts to set new national socio-scientific standards for defining, establishing, and improving data bases for minority populations, for collecting data on minorities in clinical trials, and for gathering and disseminating research data relative to minority health.

### III

**NIH should develop new and varied research methods and procedures in order to successfully address the health needs of minorities.**

NIH should strongly encourage the inclusion of many more minorities in all extramural and intramural research projects involving human subjects, including clinical trials of medical procedures, medical devices and new drugs. Data should be collected in such a manner that the impact on minority groups can be determined.

The FFT strongly recommends that NIH support the development of community-based biomedical and biobehavioral research organizations by providing early planning grants to form such groups, by having special review processes for such interdisciplinary community-based research teams and by providing incentives for established research institutions to interact with these groups.

The FFT also recommends that established research institutions be required to demonstrate that minorities and community-based organizations have been consulted and will participate in studies proposed by those institutions.

### IV

**The FFT recommends that OMP should coordinate and review all NIH programs for minorities to reduce duplication of effort, to ensure that programs meet overall guidelines, to ensure the general and timely dissemination of research results among the minority communities, and to encourage collaboration between major research institutions and minority institutions.**

The FFT fully supports the coordinating role played by OMP within the NIH research community and asks that OMP undertake even wider and more open communications about NIH activities for minorities; that it engage in strong outreach activities to form links with minorities in the biomedical community and with community-based organizations; that it review new program initiatives within NIH for their ability to impact minority problems; and that it serve as a central focus for coordinating NIH efforts with those of other government agencies also addressing minority issues.

These four major recommendations acknowledge that NIH is already expending significant effort in areas of minority health concerns. The FFT nevertheless urges the NIH to increase its support for targeted research to extend the life span of minorities and to improve their health status. All Americans—minority and majority alike—should expect to live long, happy, and productive lives.







## RECOMMENDATIONS

### V-XIII

#### Participation of Minorities in Research

The FFT agrees with NIH that the addition of more minority researchers would contribute greatly to progress in minority health. In order to achieve an increase in the number of minority investigators, NIH must recruit and train more minority students. They could form that growing pool of experienced researchers with the insight and desire to improve the health status of America's minority population. At the same time, they could strengthen biomedical research in general.

But the current reality is that the recruitment of minority students into the sciences has not been successful, that the number of minorities in training programs is extremely low, and that retention and graduation levels for science majors are well below desirable levels.

The FFT believes that real progress in this area will come only if very young minority students are exposed to—and excited by—the rewards of a career in the biomedical and life sciences. Programs must also be in place to nurture that interest and excitement throughout the students' elementary, middle and high school experience and on into higher education and career development.

Such a lifetime career path for minority scientists must lead to full integration into the biomedical research system, including service on study sections, success in the grants process, collaborative work with minority role models, additional specialty research training, publications and participation in clinical trials.

#### V

The FFT recommends that NIH make special efforts to participate in programs to improve the scientific literacy of all children in the United States, with particular emphasis on convincing more minority children to choose science as a career through interventions at the elementary and secondary school levels.

The FFT further recommends that NIH fund at least 100 Saturday Science Academies per year to introduce elementary and middle school minority students and science teachers to laboratory science and at least 50 Summer Science Enrichment Programs per year to introduce hands-on experimental science to middle and high school students and teachers. NIH should support and enhance activities for minority students at magnet high schools that specialize in career training for the health sciences as well as provide incentives and assistance for communities desiring to establish such schools. NIH should also explore innovative ways to assist adult minority scientist to serve as mentors and role models in local school classrooms with high concentrations of minority students.

#### VI

Because science teachers can play such a key role in generating enthusiasm for science among minority students, the FFT recommends that NIH cooperate in government programs that support the training and professional development of science teachers, especially minority teachers.



The FFT urges NIH to fund programs that enable minority science teachers, or teachers from schools with high concentrations of minority students, to participate in summer science training programs, to work in research labs and to pursue graduate degrees. In particular, NIH should cooperate with the National Science Foundation to develop joint programs that focus on minority teacher training. The FFT also recommends that NIH support work-shops to improve attitudes among teachers and career counselors so as to heighten their expectations of excellence from minority students who are interested in careers in science.

## VII

**NIH should support programs that significantly increase the recruitment and retention of minority science students at the pre-college and college entrance levels.**

The FFT recommends that NIH—in partnership with higher education, foundations, industry and community volunteers—expand the NIH Minority High School Student Research Apprenticeship Program (MHSSRAP) and other hands-on training programs in order to increase the number of minority student participants from an expected 3,000 in 1993 to 6,000 by 1995. The FFT also recommends NIH support for pre-freshman 'bridging' programs (university-hosted orientation and remediation courses) to help up to 600 promising minority high school graduates each year make the transition to campus life and a science curriculum. The FFT further recommends the initiation of an NIH "Minority Science Scholars Program" to award four-year merit college scholarships for up to 500 minority students per year.

## VIII

**Since a great many minority students are in two-year community and junior colleges, the FFT recommends that NIH help increase the transfer of talented minority students who have demonstrated scientific knowledge and skills from associate or technician programs at two-year institutions to baccalaureate programs in the biomedical and life sciences at four-year institutions.**

The FFT recommends that NIH support collaborative agreements between two-year and four-year institutions so that good students can begin a quality science curriculum at one institution and—if properly identified, recruited, and motivated—continue their upper-level studies at a collaborating four-year institution. All four-year schools receiving NIH support for minority training programs should be required to recruit good minority students at nearby two-year schools. In addition, two-year schools with sufficient program strength and capable advisors should be able to offer their students support similar to the Minority Access to Research Careers (MARC) program, which is currently limited to graduates of four-year institutions. (This proposal is expanded on in recommendation IX.)

## IX

**The FFT recommends that NIH continue to support the training of undergraduate minority students in the biomedical sciences. The MARC program, so successful in supporting junior- and senior-year science honor students at minority institutions, should be expanded to assist promising minority undergraduates at both minority and majority institutions, including two-year as well as four-year institutions.**



The FFT recognizes the accomplishments of the MARC program and recommends that it and/or similar programs be made available to more students (at least double the current number by 1995) at more institutions, adding positions at two-year and majority four-year institutions.

The FFT also recommends that the MARC program be evaluated in order to identify those components that are successful as well as those that need to be strengthened through improvements in design and cost-effectiveness. Such a program of evaluation and improvement would strengthen and prepare the MARC program for further expansion and innovation. The FFT recommends that four-year institutions with MARC programs be required to have a strong recruitment component at local high schools and two-year and junior colleges. They also should become partners wherever possible with two-year colleges to offer MARC support to promising minority students at those two-year and junior colleges. The FFT recommends that additional flexibility be built into the MARC program to accommodate non-traditional students and to prevent the loss of promising students at critical points in their undergraduate careers.

## X

**The FFT recommends that NIH continue to use the MARC Predoctoral Fellowship Program and its various institutional training grants to support the transition of undergraduate minority research trainees to graduate and investigator training.**

*To further expand the pool of minority predoctoral students, the FFT recommends that NIH consider taking the following steps:*

- NIH should continue support through graduate training not only for MARC trainees but also of minority science graduates who have not been in MARC programs. The stipends should be awarded to the institution of the student's choice for graduate education.
- Attributes that have been found to relate to the success of minorities in graduate schools should be given significant weight along with GRE scores.
- NIH should allow the support of up to three persons under a single Minority Investigator Research Supplement to an NIH grant, if the principal investigator is able to demonstrate his or her ability to provide a quality experience for these individuals (graduate students, teaching fellows or others).
- NIH should provide a family allowance to the minority predoctoral and postdoctoral stipends for married students if the institutional finance office determines that they could not continue their education without such support.
- NIH should consider an extra year of fellowship support for minority students who require additional course work or selective tutorial activities to qualify for entrance into doctoral-level programs.
- NIH should recognize that many minority students pursue master's degrees in the biomedical sciences rather than opting for the five-year Ph.D. program after undergraduate school (usually for financial reasons). Students who receive their master's degree should be targeted for special encouragement and support to complete the Ph.D.



- NIH should seek out talented minorities with non-traditional or interrupted educations to help them re-enter school and continue on the path of a biomedical career.
- NIH should encourage private industry to directly assist predoctoral minority scientists and technicians to obtain the master's and Ph.D. and other specialty training necessary to participate in industry's own contribution to biomedical research.

## XI

**NIH should continue funding its full array of programs supporting the professional development of minority biomedical scientist as well as evaluating those programs in order to identify their strengths and weaknesses.**

NIH should continue the MARC Postdoctoral Fellowships, the Visiting Scientist and Faculty Fellowship Programs, the Minority Research Supplement, the Minority Clinical Researcher Programs, the early grant and career development awards and the Extramural Associates program, all of which are use to advance the training and career development of minority scientists.

The Minority Biomedical Research Scientist (MBRS) program should serve as model for the development of minority research faculty. It should be evaluated for those components which have made it successful and should be strengthened by improvements in design and cost effectiveness so that it may be extended in new ways to assist more researchers.

The FFT recommends that Extramural Associates from minority institutions, who are trained by NIH, have the opportunity to return to their institutions with seed money for small research grants which would involve

faculty colleagues and thus help introduce them to the standards and processes in the competition for R01 Research Project Grant Funds.

In order to promote a general, positive environment for the success of these programs, the FFT also recommends that all grantee institutions demonstrate that they are actively recruiting, hiring and advancing minorities and including minority input into research projects dealing with minority health concerns. This is a way of assuring their own future success in the review process. NIH should set the standard by recruiting more minority investigators for its own study sections and review panels and should consider inviting non-research minorities—as appropriate—to provide their special perspectives as non-voting reviewers on minority issues.

## XII

**NIH must continue and, where possible, expand programs at institutions with significant or predominant enrollment of minorities so that some may become "centers of excellence" for quality training of minority science students and the conduct of state-of-the-art faculty research.**

The FFT recommends that NIH consider identifying and funding such "centers of excellence in minority health" which would serve as centers of leadership in the investigation of minority health problems, as major training centers for investigators interested in these areas of research and as points from which important health information would be disseminated to minority communities. Such centers could help develop and become part of a "network of excellence" linking traditional research institutions to each other as well as to community-based research organizations dealing with minority



health concerns. One model for establishing such centers is the Land Grant College Act ("Morrill Act") passed by Congress in 1862 to stimulate cooperative research and development for the benefit of an entire region. Appropriate locations for establishing such centers would include consortia of institutions that have proven success at producing minority professionals in the biomedical and behavioral sciences.

The FFT recommends that the Research Centers at Minority Institutions (RCMI) program be expanded to provide more infrastructure development at those traditional minority schools that train minority scientists, including those not offering a doctoral degree.

The FFT recommends that the Academic Research Enhancement Award (AREA) program be expanded to increase the development of the necessary infrastructures within schools which have not yet been major participants in NIH programs although they are engaged in training minority scientists.

### XIII

Finally, the FFT strongly encourages NIH to continue its historic progress along the path that leads to the

achievement of the twin goals of the NIH minority health initiative—to improve the health of minorities and to increase the participation of minorities in all phases of biomedical research.

*The FFT recognizes and firmly supports the following steps to help NIH maintain its momentum of progress:*

- The development and implementation of a comprehensive four-year plan leading to a ten-year plan - to achieve the twin goals of the NIH minority health initiative.
- The establishment of an Advisory Office of the Director.
- The dissemination of better data relative to minority health concerns not only within NIH but also between NIH and the larger research community.
- The promise of increased support for innovative ideas and projects as well as established programs on behalf of the nation's minorities.
- The commitment to achieve representative racial and ethnic diversity at every level throughout every institute, center and division at NIH.



## *Members of the NIH Minority Programs Fact-Finding Team*

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Dr. David Satcher, Co-Chair <i>Meharry Medical College</i>	Ms. Tessie Guillermo <i>Asian American Health Forum</i>	Dr. Vivian Pinn <i>Howard University</i>
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Dr. William B DeLauder <i>Delaware State College</i>	Monsignor Paul A. Lenz <i>Black and Indian Mission Office</i>	Dr. Timothy L. Taylor <i>University of Oklahoma Committee on Minority Health</i>
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Dr. Frank L. Douglas <i>Ciba-Geigy</i>	Dr. G.P. Manire <i>University of North Carolina</i>	Dr. Charles M. Veft <i>Massachusetts Institute of Technology</i>
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Dr. Calvin French <i>Church of Jesus Christ of the Latter Day Saints</i>	Dr. Art McDonald <i>Dull Knife Memorial College</i>	Dr. Charles Williams <i>National Education Association</i>
Dr. Mary Anne Frey <i>Wright State University School of Medicine Lockheed Engineering &amp; Science Co.</i>	Dr. Joseph B. Oxendine <i>Pembroke State University</i>	



## **APPENDIX II**

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### **ASSESSMENT TEAM MEMBERS AND CONFERENCE AGENDA**







## **Assessment Team**

### **OFFICE OF RESEARCH ON MINORITY HEALTH, NATIONAL INSTITUTES OF HEALTH**

### **NATIONAL MEETING ON MINORITY HEALTH RESEARCH AND RESEARCH TRAINING**

March 27-30, 1994

Chicago, Illinois

#### **Assessment Team Members**

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**OFFICE OF RESEARCH ON MINORITY HEALTH,  
NATIONAL INSTITUTES OF HEALTH**

**NATIONAL MEETING ON MINORITY HEALTH RESEARCH  
AND RESEARCH TRAINING**

**March 27-30, 1994  
Chicago, Illinois**

Sunday, March 27, 1994

**Afternoon Arrival of Conference Participants**

6:30 p.m. - 7:00 p.m.    **Presenters Meeting**  
7:00 p.m. - 8:00 p.m.    **Assessment Team Meeting**  
8:00 p.m. - 9:00 p.m.    **Plenary Session**

**Speaker:** *Dr. Donna Shalala*  
*Secretary, U.S. Department of Health  
and Human Services*

9:00 p.m. - 10:00 p.m.    **Get Acquainted Reception**

Monday, March 28, 1994

7:30 a.m. - 8:00 a.m.    **Continental Breakfast**  
8:00 a.m. - 8:30 a.m.    **Opening of Grantee Presentation Sessions**

**Speaker:** *Dr. Harold Varmus*  
*Director*  
*National Institutes of Health*

8:30 a.m. - 11:30 a.m.    **Grantee Presentations**

8:30 a.m. - 8:50 a.m.    **Duane Alexander, M.D.**  
**Director**  
**National Institute of Child Health and Human Development**

*Cooperative Community-Based Perinatal Studies and  
Interventions in Minority Populations*



8:50 a.m. - 9:10 a.m. Richard Klausner, M.D.  
Chief  
Cell Biology and Metabolism Branch  
Division of Intramural Research  
National Institute of Child Health and Human Development

*Study of Hemochromatosis in Africans and African Americans*

9:10 a.m. - 9:30 a.m. Jay Moskowitz, Ph.D.  
Deputy Director and Acting Scientific Director  
National Institute on Deafness and Other Communication  
Disorders

*Risk Determination and Epidemiology of Otitis Media*

9:30 a.m. - 9:50 a.m. Kenneth Olden, Ph.D.  
Director  
National Institute of Environmental Health Sciences

*Developmental Centers for Research on the Environmental  
Health Problems of Minority and Underserved Populations,  
Toxicity of Lead in Children, and Environmental Equity*

9:50 a.m. - 10:10 a.m. Brian Flay, M.D.  
Director  
Prevention Research Center  
University of Illinois at Chicago

*Minority Youth Health Behavior Research:  
The Development and Evaluation of Interventions*

10:10 a.m. - 10:30 a.m. **Break**

10:30 a.m. - 10:50 a.m. Lauren Wood, M.D.  
Senior Clinical Investigator  
Infectious Disease Section  
National Cancer Institute

*Minority Adolescent HIV Research*



10:50 a.m. - 11:10 a.m. Lawrence Shulman, Ph.D., M.D.  
Director  
National Institute of Arthritis and Musculoskeletal  
and Skin Diseases

*Systemic Lupus Erythematosus in Women and Minorities*

11:10 a.m. - 11:30 a.m. Kenneth Olden, Ph.D.  
Director  
National Institute of Environmental Health Sciences

*Lung Cancer in Black Americans*

11:30 a.m. - 1:00 p.m. **Lunch with Speaker**

**Speaker:** *Congressman Louis Stokes*  
*11th District, Ohio*

1:00 p.m. - 6:00 p.m. **Grantee Presentations**

1:00 p.m. - 1:20 p.m. George Counts, M.D.  
Director  
Office of Research on Minority and Women's Health  
National Institute of Allergy and Infectious Diseases

*Hispanic/Latino Asthma Study*

1:20 p.m. - 1:40 p.m. Lawrence Y. Agodoa, M.D.  
Director  
Minority Health Program, Division of Kidney, Urologic  
and Hematologic Diseases  
National Institute of Diabetes and Digestive and  
Kidney Diseases

*Recruitment and Compliance in a Minority Population -  
African American Study of Kidney Disease and  
Hypertension*



1:40 p.m. - 2:00 p.m. Luther Williams, Ph.D.  
Assistant Director for Education and Human Resources  
National Science Foundation

*Comprehensive Regional Centers for Minorities  
Partnerships for Minority Student Achievement*

2:00 p.m. - 2:20 p.m. Marvin Cassman, Ph.D.  
Acting Director  
National Institute of General Medical Sciences

*2 year/4 year Bridges to the Future*

2:20 p.m. - 2:40 p.m. Henry Dearman, Ph.D.  
Program Director  
University of North Carolina-Chapel Hill

*M.S./Ph.D. Bridges to the Future*

2:40 p.m. - 3:00 p.m. David A. Wolff, Ph.D.  
Chief  
International Research and Awards Branch  
Fogarty International Center

*Minority International Research Training Program*

3:00 p.m. - 3:20 p.m. **Break**

3:20 p.m. - 3:40 p.m. Sidney McNairy, Ph.D.  
Program Director  
National Center for Research Resources

*Research Centers in Minority Institutions*

3:40 p.m. - 4:00 p.m. Anthony A. Rene, Ph.D.  
Assistant Director for Referral and Liaison  
National Institute of General Medical Sciences

*Minority Research Supplements*



- 4:00 p.m. - 4:20 p.m. Adolph Falcon  
Vice President for Policy and Research  
National Coalition of Hispanic Health and  
Human Service Organizations  
  
*National Hispanic Leadership Initiative on Cancer*
- 4:20 p.m. - 4:40 p.m. Clarice Reid, M.D.  
Chief  
Sickle Cell Disease Branch  
Division of Blood Diseases and Resources  
National Heart, Lung, and Blood Institute  
  
*Sickle Cell Disease Research*
- 4:40 p.m. - 5:00 p.m. Clive O. Callender, M.D., F.A.C.S.  
Principal Investigator  
Howard University  
  
*National Minority Organ Tissue Transplant Education Program*
- 5:00 p.m. - 5:20 p.m. George Blackburn, M.D., Ph.D.  
Principal Investigator  
Harvard Deaconess Hospital  
  
*Long-Term Outcome of Obesity Treatment in  
Minority Women*
- 5:20 p.m. - 5:40 p.m. Thomas Buchanan, M.D.  
Principal Investigator  
Los Angeles County-University of South California  
  
*Pathogenesis of Non-insulin Dependent Diabetes  
Mellitus (NIDDM) in Mexican American Women*
- 5:40 p.m. - 6:00 p.m. Thomas Prohaska, Ph.D.  
Principal Investigator  
University of Illinois at Chicago  
  
*Exploratory Center Grants for Research on Health Promotion  
in Older Minority Populations*



6:00 p.m. - 6:30 p.m. Marvin Cassman, Ph.D.  
Acting Director  
National Institute of General Medical Sciences

*Minority Biomedical Research Support Program  
Minority Access to Research Careers*

7:30 p.m. - 9:00 p.m. **Group Dinner**  
**Speaker:** *Congresswoman Cardiss Collins  
7th District, Illinois*

Tuesday, March 29, 1994

7:30 a.m. - 8:00 a.m. **Continental Breakfast**

8:00 a.m. - 9:00 a.m. **Speaker:** *Dr. John Ruffin  
Associate Director  
Office of Research on Minority Health*

9:00 a.m. - 9:15 a.m. **Break**

9:15 a.m. - 11:00 a.m. **Breakout into Sections for Discussion of Health Research**

11:00 a.m. - 12:30 p.m. **Section Reports on Health Research**

12:30 p.m. - 1:30 p.m. **Group Lunch**

**Speaker:** *Congressman Luis Gutierrez  
4th District, Illinois*

1:30 p.m. - 3:15 p.m. **Breakout into Sections for Discussion of Biomedical  
Training/Education Programs**

3:15 p.m. - 3:30 p.m. **Break**



3:30 p.m. - 5:00 p.m.    **Section Reports on Biomedical Training/Education**

5:00 p.m. - 5:15 p.m.    **Adjournment**

**Departure of Conference Participants**

Wednesday, March 30, 1994

8:30 a.m. - 5:00 p.m.    **Assessment Team Meeting**







## **APPENDIX III**

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### **ABSTRACTS OF CONFERENCE PRESENTATIONS AND RELATED ORMH-SUPPORTED RESEARCH AND TRAINING ACTIVITIES**







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## **African American Study of Kidney Disease and Hypertension**

**Lawrence Y. Agodoa, M.D.**

**Director, Minority Health Program**

**Division of Kidney, Urologic and Hematologic Diseases**

**National Institute of Diabetes and Digestive and Kidney Diseases**

### **Background:**

End-stage renal disease (ESRD) is an important health problem among African Americans. In 1990, Blacks (African Americans) made up 29 percent of the ESRD cases although only about 12 percent of the U.S. population was Black. The ESRD incidence rate for Blacks is nearly four times that of whites (518 per million versus 132 per million). The disparity between Blacks and whites is especially striking for hypertension-related ESRD. The incidence rate of ESRD with a diagnosis of hypertension, the leading cause of renal failure among Blacks, is 6.2 times greater than in whites. For certain age groups, the disease rates are particularly high. For example, among Blacks aged 25-44, the incidence rate of ESRD associated with hypertension is 18 times greater than the rate for whites in 1988-90; the rate for Blacks 45-64 years old is nearly 10 times that of whites. This disease burden prevails despite the fact that improved control of blood pressure has been responsible, in part, for a decrease in incidence of and mortality from myocardial infarction and from stroke among both Black and white Americans during the past decade.

The disproportionate number of cases of ESRD among Blacks ascribed to hypertension has been attributed to a number of factors, including higher prevalence of and more severe hypertension, greater susceptibility of the kidney to elevated blood pressure, and difficulty in accessing treatment services, among others. Despite uncertainty about the reason(s) for this preponderance of disease, there are reports that control of blood pressure to 140/90 mm Hg (mean arterial pressure or MAP of 107) or less is beneficial in reducing the progression of kidney disease to end-stage. It is important to note, however, that a rigorously controlled clinical trial has not yet been conducted in persons with established renal impairment resulting from hypertension to determine whether one class of antihypertensive agents protects the kidney better than another and to determine the optimum blood pressure level that maximally protects the kidney.

Recently, several reports have highlighted the benefits of antihypertensive therapy in preventing loss of renal function among persons with established kidney disease. For example, although only a modest difference in the rate of loss of renal function (as measured by serum creatinine) was observed between the Stepped-Care (SC) and Referred Care (RC) groups (21.7/1,000 in SC survivors and 24.6/1,000 in RC survivors) in the Hypertension and Detection Follow-up Program, a 50% relative difference in favor of SC among participants with baseline serum creatinine concentration indicating borderline hypercreatinemia (1.50 -



1.69 mg/dl) was observed. Of particular interest was the significantly greater rate of developing hypercreatinemia in Blacks, men, and older persons (>60 years of age) and among persons with higher diastolic blood pressure at trial entry.

An encouraging preliminary report from a single-center clinical trial, which enrolled a high percentage of Blacks and utilized an accurate measure of kidney function, also suggests that lowering blood pressure in patients with hypertensive kidney disease may slow loss of kidney function. However, this study reported results from only a subset of randomized patients, lacked a control or comparison group, and failed to achieve a difference in level of blood pressure control.

Since most, if not all, of the antihypertensive clinical trials conducted to date have focused primarily on cerebrovascular and cardiovascular events, a randomized controlled clinical trial is necessary to define the clinical usefulness and possible renal protective effects of long-term therapy with the major blood pressure lowering drugs in patients, especially African Americans, with hypertension associated with the impaired renal function. The benefit to renal function of control of blood pressure to levels below those generally recommended (140/90 mm Hg) also needs to be assessed.

### **Objectives:**

The clinical trial, African American Study of Kidney Disease and Hypertension (AASK), was initiated to determine:

1. Which class(es) of antihypertensive agents, if any, is (are) most effective in retarding progression of kidney disease in African Americans with established kidney dysfunction, and hypertension. The three major classes to be investigated are Beta Blockers, Calcium Channel Blockers, and Angiotensin Converting Enzyme Inhibitors.
2. An effective level of controlled blood pressure whereby progression of established kidney disease can be slowed. The intention is to examine whether one of two levels of blood pressure control ( $\leq 92$  mm Hg vs. 102-107 mm Hg) better preserves renal function.
3. (In the Pilot Study) The most effective strategies in recruiting African Americans for clinical trials, and what factors enhance retention and adherence to clinical trial protocol.

The study is a randomized, double-blind (full-scale) clinical trial with a 3 X 2 factorial design.



### **Target Population:**

The individuals eligible for the study will be African Americans with hypertension (treated or untreated), and established renal functional impairment. Participants will be between the ages of 18 and 70. Hypertension is defined as sitting blood pressure of 95 mm Hg or more. Reduced renal function is defined as a pre-randomization  $^{125}\text{I}$ -iothalamate glomerular filtration rate between 25-70 ml/min/1.73m<sup>2</sup>. Selected exclusion criteria include history of malignant or accelerated hypertension within 6 months prior to study entry, known secondary causes of hypertension, known history of diabetes mellitus type I and II, and a ratio of urinary protein (mg/dl) to creatinine (mg/dl) exceeding 1.5 in a 24-hour urine sample.

### **Implications:**

In the short term, data from the pilot study will provide information on relatively effective strategies that encourage participation of African Americans in clinical trials. Lessons learned may help future clinical trials in this population. The pilot data will also provide useful information on the effectiveness of the antihypertensive regimens, and the feasibility of attaining the low mean arterial blood pressure goal of 92 mm Hg.

In the long term, the study will provide information on the effectiveness of an antihypertensive regimen in slowing progression of established kidney disease in African Americans. Equally importantly, the results of the study may provide data on a "safer" level of blood pressure at which target organ damage is reduced in African Americans.

### **Progress:**

The pilot recruitment phase of the clinical trial began in June/July 1993. The seven participating clinical centers were assigned specific recruitment strategies in addition to the usual strategies of chart review and physician referral. Each clinical center was asked to pilot two of three recruitment strategies: mass mailing, mass media, and community screening. Church-based recruitment was discussed but could not be implemented for a variety of reasons. However, plans are being discussed to explore the possibility during the early phases of the full-scale trial. Preliminary results suggest a relative ineffectiveness of mass mailing as the source of patient recruitment compared with the other strategies. For this particular study, physician referral (in-house and external) appeared to be the most effective means of recruiting patients.

Recruitment and randomization concluded at the end of February 1994. Patient follow-up is in progress and will conclude at the end of May 1994, and data analysis of the pilot phase carried out through the end of June 1994.



**Future Plans:**

The full-scale clinical trial is scheduled to begin in July 1994. A request for application (RFA) was issued in October 1993 for clinical centers and a data center. 44 applications were received in response to the RFA, and are being reviewed. Plans are to support 14 clinical centers and a data center. Approximately 900 patients are to be recruited and randomized over 24 months, and treated and followed for approximately 5 years. The full-scale study design will be similar to that of the pilot study.



## **Cooperative Community-Based Perinatal Studies and Interventions in Minority Populations**

**Duane Alexander, M.D.**

**Director**

**National Institute of Child Health and Human Development**

Support from the Office of Research on Minority Health has enabled the National Institute of Child Health and Human Development (NICHD), with assistance from the National Institute of Nursing Research (NINR), to launch a program aimed at reducing the disproportionately high rate of infant mortality among minority populations. This rate among African Americans is approximately twice the rate in whites, and the gap may be widening, especially in inner cities. The District of Columbia for some years has had a worse infant mortality rate than any of the 50 states, a fact which, combined with its proximity to the National Institutes of Health, made it an appropriate site for a research program to address the problem. The program of research developed constitutes the infant component of the ORMH Minority Health Initiative.

Rather than basic or clinical research, which is supported by other mechanisms, the focus of this program is to develop and test community-based evaluations and interventions intended to reduce infant mortality in a way that can be scientifically assessed and the results applied in other locations. The approach has been to use the cooperative agreement grant mechanism to bring together institutions in the District of Columbia with NICHD professional staff in epidemiology and prevention research. They have then worked together to identify topics for study, develop and refine protocols for the studies, implement them, and evaluate the results.

The Request for Applications for the cooperative agreement grants was issued in FY 1992. In a competitive process, grants to participate in this process were awarded to the D.C. Commission of Public Health, Howard University, D.C. General Hospital, D.C. Children's Hospital/George Washington University, Georgetown University, and the University of the District of Columbia, along with a data coordinating center (RTI). Funding so far has supported the infrastructure and planning process; funds will be budgeted to institutions to implement individual protocols as they come on line. Nearly 150 scientists from these organizations and the NIH have been involved in protocol development. Many of the investigators are minorities, and for some it is their first research design experience, so these grants are providing a useful training and career development role as well. To date, three protocols have been completed and approved by the outside Scientific Advisory Board, and are being prepared for implementation this spring. These initial studies involve parenting education, increasing immunization, and health services evaluation. Other protocols under development will focus on interventions for injury prevention, adolescent pregnancy, risks for preterm labor, barriers to prenatal care, and comprehensive prenatal care.



At this point, the basic concept underlying this program, i.e., bringing together the major health organizations in the community to work cooperatively to develop and test solutions to the problem of infant mortality among minorities, appears to be working. We are eager to implement our first protocols in this process made possible by ORMH funding.



**Reducing Tobacco, Alcohol, and Drug Abuse  
In Minority Populations Through Family-Based Skills Training**

**Lula Beatty, Ph.D.,  
Prevention Research Branch  
Division of Epidemiology and Prevention Research  
National Institute of Drug Abuse**

**Overview:**

Consistent with the NIH objective to promote health in minority communities, the purpose of this supplemental project is to develop and evaluate a parent intervention program designed to prevent tobacco, alcohol, and drug use in urban minority communities. This project will expand the work we are currently doing as part of a NIDA-funded Center grant to Cornell University Medical College. The parent intervention will be based in large part on a parent video developed as part of the Center, but will be expanded to include written support materials and suggested parent-child communication exercises. Like the video, the parent intervention will be based on state-of-the-art prevention technology designed to reduce risk factors (e.g., normative expectations) and promote protective factors (e.g., resistance skills).

**Significance and Rationale:**

Tobacco, alcohol, and drug abuse are among the most significant health problems facing this country. National survey data consistently indicate that these substance are commonly used by high school seniors (e.g., Bachma et al., 1991). Health problems associated with tobacco, alcohol, and drug abuse are particularly problematic for minority populations. For example, African-American adults have higher drug-related mortality than whites (USDHHS, 1986). Most IV drug abusers (over 60%) in the greater New York City areas are African-American or Hispanic. Of reported AIDS patients who are IV drug abusers, 51% are African-American and 30% are Hispanic (MMWR, 1986). Drug abuse is also an important factor associated with school drop-outs and violence among African-American youth. Among these populations, African-American and Hispanic youth living in housing projects and homeless shelters are at particularly high risk. This study will provide important new information concerning a parent intervention which when used either alone or in combination with interventions targeting their children will reduce tobacco, alcohol, and drug abuse among minority youth. Thus, as such, this project offers the potential of significantly contributing to the improvement of the health status of minorities.

**Design:**

This project will include a 3-month developmental phase and 3-month pre-post experimental study. During the developmental phase the written support materials and suggested activities



will be developed and evaluated using two focus groups with Latino and African-American parents. For the pilot study, 400 parents of children between the ages of 10-15 will be recruited from 2 sites: shelters for homeless families and housing developments. A brief survey will be developed for parents and children to assess normative expectations regarding smoking, drinking, and drug use, attitudes towards substance use and knowledge about drugs and drug prevention strategies. In addition, the parent survey will assess parenting style as well as the extent to which parents have spoken to their children about drug use and what they have said. The child survey will also assess the extent to which children say their parents have spoken to them about drug use and what they said, as well as assessing tobacco, alcohol, and drug use behavioral intentions.

As part of the NIDA Center Grant projects, the shelters and housing developments have been assigned to experimental and control conditions, and these conditions will be maintained for this project. In the experimental project, parents will receive the parent intervention including the video. In the control condition, parents will receive a comparable length self-help video which does not address smoking, drinking, drug use or communications skills. In the shelters and in the housing developments, parents will watch the video in a common area designated to these projects. All participating parents and children will complete the brief survey prior to viewing the video, and again, one month later. Parents will receive \$15 for their participation and children will receive \$5.

#### **Data Analysis:**

The parent drug-abuse prevention program will be tested for efficacy in changing mediating and behavioral variables. The extent to which the parent intervention program results in increased communication between parents and children regarding drug use in the experimental condition relative to the control condition will be examined. Parent predictors of children's drug use will also be studied. In the homeless shelters we have already collected extensive information from participating parent and child pairs concerning both parent and child tobacco, alcohol and drug use, normative expectations, problem solving, interaction styles, as well as a range of psychosocial risk and protective factors. This data from the homeless shelter project will be linked to the survey data to be collected as part of this project.

#### **Conclusion:**

This project has the potential to develop an effective parent intervention program which would be designed to reduce drug use in urban-minority communities. This project overcomes many of the barriers to effective parent programs in that it is contained on video and therefore available to parents at their convenience. Moreover, this program will be very flexible, and could serve as a stand-alone program, or be used as a complement to school-based or community-based prevention approaches for youth.



## **Long-Term Outcome of Obesity Treatment in Minority Women**

**George L. Blackburn, M.D., Ph.D.  
Principal Investigator  
Harvard Deaconess Hospital**

Obesity is a health problem at all levels of the lifespan. the Report of the Secretary's Task Force on Black and Minority Health has found that overweight is already a problem for 44% of black women aged 20 and older. (1) However, black women in particular appear to be at greatest risk for weight gain in their second and third decades of life. Williamson et al. have estimated that the incidence of major weight gain ( $\leq 10\text{kg}$ ) was 50% higher in blacks than in whites. The same studies among women who were obese at baseline indicated that blacks were 60% more likely to become obese than whites (2). The National Health and Nutrition Survey II (NHANES) identified the prevalence of overweight was much higher among black females compared to white females (19.6% and 9.6% respectively) (3). The highest prevalence of severe overweight was 26.3% which was among black females.

Children are not immune to obesity. In particular, studies of body fat distribution have indicated trunk fat (apple shape) associated with disorders of intermediate metabolism for hyperinsulinism and insulin resistance. Kikuchi et al. have found unusually high insulin levels in black girls aged 5-17, which appears to be a contributory factor to the development of diabetes in black Americans (4). Research by Berenson, has found that obese adult black females begin to manifest obesity around 10 years of age (5). While boys lose subcutaneous fat during adolescence, girls continue to deposit fat which places them at a greater risk for adult obesity (6). More research is necessary from childhood through adolescence to determine health consequences of overweight childhood and adolescence.

Dietz (7) has noted a USDA report that school lunch supplies 30% of the daily caloric requirements from children and adolescents aged 10-15. This represents the largest setting in the US for feeding a large percentage of children. However, these lunches exceeded the recommendation for fat ( $>30\%$  of daily calories), with fast foods from McDonalds as popular choices on school menus. Dr. Dietz suggests that we begin prudent nutrition education by implementing national guidelines for limiting fat content in school lunches.

The Department of Health and Human Services in Healthy People 2000 have identified Physical Activity and Nutrition as the top two objectives of health promotion (6). This emphasis is largely due to the risk factors associated with obesity. Severe overweight increases the risk for high blood cholesterol, high blood pressure and diabetes. It also increases the risk for gallbladder disease and for some types of cancer (breast, prostate and colon). In addition to these health consequences, obesity can lead to significant psychosocial



and emotional problems (3). Based on these serious risks, the Surgeon General of the United States has cited the prevention and treatment of obesity as a national health priority.

Given early onset of obesity, prevention requires screening for excess body fat throughout the lifespan. The Report of the U.S. Preventive Services Task Force has developed clinical efforts that can be made throughout life to improve nutrition status and overall health (8):

Birth to 18 months	Parent counseling on nutrient intake, focus on iron-rich foods.
2-6 years	Parent and patient counseling on nutrient intake (limiting sweets and between meal snacks), caloric balance, selection of exercise program.
7-12 years	Counseling should focus on reducing fat sources in the diet and the selection of an exercise program.
13-18 years	Continue as stated above
19-39 years	Continue to focus on the reduction of fat. Increase complex carbohydrates, fiber, sodium and calcium in the diet. Continue with a regular exercise program.
40-64 years	Continue as stated above.
65 + years	Continue as stated above.

The U.S. Preventive Services Task Force has determined that primary prevention to reduce risk factors such as poor nutrition and physical inactivity show greater promise for improving the health of Americans (8).

*Long-Term Outcome of Obesity Treatment in Minority Women* is a well-designed, controlled, randomized clinical trial that is specifically examining issues of weight control and prevention of disease for the African American woman. Women aged 40 to 64 show increased risk for obesity-related diseases (8). The National Center for Health Statistics found that 55% of middle-aged black women were significantly overweight (9). Because of their strong family association as the caretaker for their children, grandchildren and other family members, they act as the "gatekeepers" to teach and actually live the healthy lifestyle they have been taught through the intervention. Through them we suspect an ability to send the message of improved health and fitness to a broader range of the population. Also, as the "sandwich generation," these women have the responsibility of elderly parents as well as their children and grandchildren.

This study being conducted at four sites (MA, CA, NY, TX), is investigating the ability of a culturally sensitive weight control program to produce a 5-10% weight loss in obese (BMI 30-40), working class African American women that can be sustained for a minimum of one year; this program was developed and piloted in a feasibility study (10). The secondary



objective is to use dietary change to reduce risk factors for disease. The long-term goal is to improve health in this population by teaching the skills necessary to sustain the type of lifestyle change recommended by the U.S. Department of Health and Human Services in Healthy People 2000. Additional outcome variables include blood pressure, fasting insulin and glucose levels, fasting total and HDL, cholesterol and triglyceride levels, exercise, habitual dietary intake, psychologic and behavioral measures, and compliance to the diet.

Eligible women will be randomized to one of three groups: 1) "Healthy Lifestyle" arm (n=200), which will receive the U.S. Dietary Guidelines and Food Guide Pyramid and will be asked to attend milestone data collection visits only; 2) Food Based Diet (FBD, n=200), which will provide 1200  $\pm$  calories through a balanced diet based on the Food guide Pyramid; 3) Prepared Food Diet (PFD, n=200), which will receive the same diet as the FBD group but will receive a minimum of 10 prepared foods a week (entrees, shakes, cereals). Subjects in the latter two arms will participate in the Black American Lifestyle Intervention (BALI) program, a 16-week active weight loss phase (weekly group education and exercise) followed by two years of monthly relapse prevention. Milestone data will be collected at baseline and at Weeks 16, 52, and 104; body weight will be measured in all subjects at Weeks 26 and 78 as well. Milestone data will include weight and BMI; body composition (BIA and skinfolds) and fat distribution (WHR; blood pressure; fasting insulin, glucose, and lipid profile; exercise levels; dietary intake (FHFFQ); compliance; psychologic assessment; and intercurrent health events. The statistical design will permit study differences in weight and other milestone data among the three groups and over time.

Each site is actively randomizing into the trial women who express enthusiasm when they realize the study has been specifically designed for African Americans. They are surprised at the resources available that focus on improving their overall health. Group sessions are led by an African American nutritionist who discusses nutrition, exercise and behavior modification in a relaxed, friendly atmosphere. The women have become empowered to make changes not only in their lifestyle but also in that of their families.

The BALI trial has been a stepping stone for supplemental grants and community outreach. A supplementary application to the *Long-Term Outcome of Obesity in Minority Women* proposes to examine insulin resistance and ethnic background in terms of genetics and weight loss outcome.

In addition to higher rates of obesity, African American women have a lower prevalence of breast cancer but a higher death rate even when controlling for stage, grade and other recognized biomarkers (11). We hope to recruit African American women who suffer from breast pain and to determine its cause and any link to the development of cancer.

Finally, prostate cancer is a significant concern from the black population as 85% of men have a greater chance of being diagnosed with prostate cancer and a 114% greater chance of



dying from it than do white men (12). To address this critical issue, we have proposed a randomized, multi-center protocol recruiting 1,000 men who have prostate cancer. Special message will be used to increase enrollment and retention of African American men.

Community involvement is paramount in providing primary prevention to those who have the potential to benefit from these interventions. In Boston, we have joined with the Harvard Street Neighborhood Health Center to recruit African American men and women into ongoing studies. Harvard Street specializes in services for all members of the family, especially for the male, and has subsequently developed the Black Male Clinic. Efforts to prevent prostatic disease have led to the organization of a prostate cancer screening initiative at Harvard Street. This intervention which is the most successful to date (12), led to the identification of abnormal findings that would otherwise have gone undetected. This type of outreach is essential and by implementing similar programs that focus on empowerment through education, we can then improve the health of the community.

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## **Pathogenesis of Non-insulin-dependent Diabetes in Mexican American Women**

**Thomas A. Buchanan, M.D.**

**Principle Investigator**

**Los Angeles County - University of Southern California**

### **Background and Objectives:**

Non-insulin-dependent diabetes mellitus (NIDDM) is a major health problem in the United States, particularly in the growing Mexican-American population. Age-adjusted prevalence rates of NIDDM among Mexican-American men and women aged 24-64 years have been reported to be 8-11%, rates that are 2-3 times those of non-Hispanic whites. In addition to the impact of NIDDM on the general well-being of afflicted patients, the disease causes significant morbidity and mortality from complications affecting the eyes, kidneys, nerves, heart, and blood vessels. The identification of people at risk for NIDDM and the prevention of diabetic complications has assumed a prominent position in the overall health care of Mexican-Americans. One high-risk group of Mexican Americans already has been identified: women with a history of mild diabetes during pregnancy (gestational diabetes or "GDM"). Follow-up studies of those women at our institution indicate that more than 10% of them develop NIDDM each year during the first 4-5 years after pregnancy. Thus, more than 50% of our patients with GDM can be expected to develop NIDDM within five years after their index pregnancy. That fact indicates a great need for the development and implementation of therapeutic strategies to prevent or delay NIDDM and its complications in Hispanic women who have had GDM. In that regard, the three major objectives of our ongoing research program are to:

1. identify characteristics that will tell us which women with GDM are among the 50% who are most likely to develop NIDDM within 3-5 years after pregnancy;
2. determine the mechanisms that lead to NIDDM in those high-risk women; and
3. develop and test interventions that can prevent or delay the development of NIDDM in our very high-risk patients.

### **Target Population:**

Mexican American women who have gestational diabetes during a current pregnancy.



### **Implications of the Work:**

Our currently funded project (*Pathogenesis of Non-insulin-dependent Diabetes in Mexican American Women*) is designed to accomplish the first two objectives listed above. We are recruiting Mexican American women who are pregnant and who are diagnosed with gestational diabetes. The women who qualify and are willing to participate in the study undergo testing during pregnancy to characterize the ability of their pancreas to secrete insulin, the effect of that insulin to regulate their blood glucose, and their degree of obesity. The women are then followed for up to five years after pregnancy to determine which ones develop diabetes and which ones do not. After we have determined who actually develops diabetes, we will analyze the initial data obtained during and soon after pregnancy to identify characteristics of "pre-diabetic" patients. Those characteristics should tell us what goes wrong during the earliest stages of development of NIDDM. When we know what goes wrong, we can develop and test interventions that are likely to prevent or delay the onset of NIDDM in a significant number of patients.

### **1993-94 Accomplishments:**

The study got underway in September of 1993. Thus far, we have had very enthusiastic support from our patients with gestational diabetes. Despite the fact that participation in the study requires several visits to the Clinical Research Center with intravenous lines, blood drawing, and complicated body composition studies, more than 75% of the qualified women have agreed to participate. We have already completed the baseline studies on nearly 50 of the 115 gestational diabetic patients that we plan to enroll. As part of the initial studies, we have developed valid protocols for measuring insulin action and hepatic glucose production in pregnant women and we have presented those protocols at scientific meetings of the American Diabetes Association and the American Federation for Clinical Research. The real "pay-off" of the work will come at the end of the current study, when we can identify the factors that lead to the development of NIDDM in our high-risk patients and begin to develop methods to prevent or delay the diabetes and its morbid complications.



## **The National Minority Organ and Tissue Transplant Education Program (MOTTEP)**

**Clive Callender, M.D., F.A.C.S.  
Principal Investigator  
Howard University**

The National Minority Organ and Tissue Transplant Education Program (MOTTEP) is charged with designing for national use, a model organ/tissue donation strategic plan and educational program which when implemented, will increase the number of minority Americans who:

1. sign donor cards;
2. have family discussions to express their desire to become organ and tissue donors; and
3. become organ and tissue donors.

Historically, blacks donated organs and tissues less often than whites. To answer the questions as to why blacks did not donate, we formulated and implemented an earlier research project which assessed attitudes about organ and tissue donation among African Americans.

Although the project was in no way intended to produce estimates of proportions of people displaying various attitudes, findings from that first project revealed that there are five prevailing issues/concerns among African Americans which generally preclude them from donating organs and tissues:

1. Lack of knowledge/awareness (about organ and tissue transplant activities);
2. Religious beliefs;
3. Mistrust of the medical community;
4. Fear of premature declaration of death after signing an organ/tissue donor card; and
5. Racial prejudice (i.e. preference that organ/tissues donated by a black donor go to a black recipient)

We then developed Black donor education programs. MOTTEP evolved from these successful Black donor programs (DCODP - 1982; DOW TIP - 1986-1992) to erase these obstructions by community based grass roots education and empowerment efforts which emphasize a minority targeted message taken by community-donors, recipients, transplant coordinators or their family members.

MOTTEP has three primary goals incorporated as a part of its strategic approach to increasing the number of minority donors over a five year period:



1. To increase transplant awareness in minority communities across the nation by educating minority communities on facts about organ/tissue transplantation by using minority community transplant recipients, donors, transplant coordinators and their families as messengers.
2. To increase the number of minority donors and transplant recipients in regional and national minority communities by empowering minority communities to develop programs which allow them to become involved in addressing issues such as access, inequity and the shortage of organs; and
3. To establish cooperative relationships with public and private sector organizations in the campaign to educate minority Americans about organ and tissue transplantation.

With over thirty-two thousand patients in the U.S. on transplant waiting lists, at least 42% of those waiting and dying are of minority origin while only 22% of the available donor pool represents minority donors. The number one problem in transplantation today is the lack of available organs and tissues. We must guarantee as many people as possible the right to donate their organs/tissues and the right to an improved quality of life. No one has to or should die waiting for an organ or tissue transplant.

Through a national education and awareness campaign such as MOTTEP, minority communities, including African Americans (Blacks), Hispanic Americans (Latinos), Native Americans (American Indians), Asian Americans and Pacific Islanders will have the opportunity to become aware of the national implications, and preventive measures which may have a favorable impact on lifestyles and practices which put them at risk for premature death, disease and chronic and debilitating conditions (i.e. Diabetes mellitus, hypertension, chronic renal failure, etc.).

The use of culturally sensitive and ethnically similar messengers is vital to such a campaign. These messengers will include persons who are known and respected within their communities; recipients; donors; families and persons on transplant waiting lists. They will deliver the message via a grassroots community based coalition which addresses their specific and unique educational needs not only related to transplantation but a variety of health care issues as well.

Benefits of the National Minority Organ and Tissue Transplant Education Program:

**Primary: Increasing the donor rate by 5% per minority per year can enhance the quality of life for all Americans in that an increase in the available donor pool does not merely benefit minorities.**



**Secondary: Costs savings! Dialysis costs \$100/day/patient or \$32,000 per year or \$72,000 per two years. Kidney transplantation costs \$30/day/patient or \$54,000 per two years.**

**The dollar benefit over a five year period for kidney transplantation as compared to dialysis represents a cost savings of 50-80 million dollars and if extra renal transplants are considered - even heart, lungs, etc. - will exceed 1 billion dollars.**

The MOTTEP contract award of over \$400,000 for the first year will allow for the establishment of local/regional programs in three (3) cities: Cleveland, OH; Los Angeles, CA; and Birmingham, AL. Plans are also under way to establish local programs in twelve (12) other cities within the second year. These cities which as well have large minority populations are Atlanta, GA; Brooklyn, NY; Dayton, OH; Delaware Valley; Detroit, MI; Hawaii; Kansas City, MO; Memphis, TN; Oakland/San Francisco, CA; Richmond, VA; Washington, DC.

MOTTEP provides a unique opportunity for transplant and health care professionals to interact directly with members of the community as we engage on a quest to improve the quality of life for all Americans but especially minority Americans.

#### **1993-94 Accomplishments:**

As a result of media visibility, oral presentations, and precocious forerunners of MOTTEP (D.C. Organ Donor Program and the DOW Take Initiative Program), an amazing increase in donation on part of minorities was achieved, (i.e. 3%, 1982 to 11.6% 1993 in African American donors and 5% to 9% in Hispanics). Therefore, MOTTEP has continued to use the same strategies to help increase awareness.

MOTTEP has made 29 oral presentations since its inception including the American Society of Minority Health and Transplant Professionals; featured in 27 news articles; performed 6 radio interviews and 7 television interviews including the Oprah Winfrey Show. In October 1993, MOTTEP was given the opportunity to co-sponsor a weekly radio broadcast on WOL 1450 AM on Friday nights from 7PM - 9PM. These programs are designed to educate the community. The program has broadcasted 19 shows and featured 33 health topics thus far.

#### **Upcoming Events:**

During the months of March, April and May 1994, MOTTEP will be launching three consecutive campaigns targeted to increase organ/tissue donor awareness as well as organ/tissue donor percentages. They include a "Heroes" campaign designed to honor persons who have made great contributions to the transplant arena; "Corporate Campaign" targeting minority owned business and its employees; and a "Donor Awareness Campaign" to target the minority general public.







## **NIGMS Minority Programs and Accomplishments**

**Marvin Cassman, Ph.D.**

**Acting Director**

**National Institute of General Medical Sciences**

The National Institute of General Medical Sciences (NIGMS) has had a long-term commitment to addressing, and ameliorating, the underrepresentation of minority groups in the biomedical sciences. In addition to the efforts made by each NIGMS program to encourage and support minority participation, the Institute has a number of special activities devoted to increasing the number of minority biomedical scientists and the research capabilities of institutions with substantial minority enrollments. NIGMS is also a leading participant in the NIH-wide program that provides supplemental funds to research grants for the support of minority scientists, students, and postdoctoral fellows.

The NIGMS Minority Access to Research Careers (MARC) Program supports biomedical research training for students and faculty at institutions with substantial minority enrollments. Its components include a program for honors undergraduates, predoctoral fellowships, faculty fellowships, and grants to support visiting scientists. As of FY 1993, about 3,499 students had participated in the honors undergraduate program, 241 faculty members had received training and/or degrees through the faculty fellowship program, and 204 students had received MARC predoctoral fellowships.

The Minority Biomedical Research Support (MBRS) Program strengthens the research capabilities of minority institutions through the support of faculty research projects on which students participate. Using funds from NIGMS and other NIH institutes, MBRS supports 101 institutions in the United States and its territories. In FY 1993, about 683 faculty members and 1,352 students participated in 589 MBRS research projects.

The MARC and MBRS Programs have existed as separate entities since 1972. Their related missions prompted the establishment, in 1991, of the NIGMS Minority Opportunities in Research (MORE) Programs Branch, which provides general administrative oversight and direction for both MARC and MBRS. In addition, the MORE Programs Branch strives to build networks; enhance communication; and facilitate the development of conferences and other activities among individuals and institutions from the scientific, academic, and business communities who share a common interest in rectifying the underrepresentation of minority groups in biomedical research.

One special MORE initiative, which is co-funded by other NIH components, is a program of national predoctoral fellowships for minorities. In the first 3 years of this effort, 234 fellowships were awarded. It is expected that at least 50 more national predoctoral fellowships will be awarded in FY 1994.



The branch has also mounted a series of regional workshops to encourage participation by academic institutions that are not presently supported by either the MARC or the MBRS Program. The workshops permit exchanges of information regarding successful program models, help participants learn how to design competitive proposals, and form the foundation for future working relationships.

In cooperation with the NIH Office of Research on Minority Health, the MORE Programs Branch administers two separate but related efforts in which minority students in 2-year colleges and in institutions offering up to the master's degree are encouraged to advance to the next level toward careers in biomedical research. This program, called "Bridges to the Future," promotes partnerships between institutions to foster transitions from the associate's to the bachelor's degree and from the master's to the doctoral degree. It has made 40 awards since its establishment in FY 1992, and 30-40 more awards will be made in FY 1994.



## **Hispanic/Latino Asthma Projects**

**George Counts, M.D.**

**Director, Office of Research on Minority and Women's Health  
National Institute of Allergy and Infectious Diseases (NIAID)**

Project Summaries of Minority Asthma Projects jointly sponsored by the National Institute of Allergy and Infectious Diseases, National Institutes of Health and the Office of Research on Minority Health for the National Conference on Minority Health Research and Research Training, Chicago, IL, March 27-29, 1994.

### **HISPANIC/LATINO ASTHMA STUDY**

Enhancing the Care of Latino Children With Asthma

#### **PRINCIPAL INVESTIGATORS**

Drs: Charles E. Lewis, Mary Ann Lewis, Gary Rachelefsky, University of California, Los Angeles.

#### **Objectives of the Project:**

1. Teaching asthmatics and their families asthma self-management using the program "Asma Control y Tratamiento Para Los Ninos".
2. Organizing the local Latino community to increase the parents' role in the identification of asthmatics, appropriate and effective use of medical care, the teaching asthma self-management skills to other asthmatics, and the development of community-support networks for asthmatics.
3. Establishing continuing education programs on asthma treatment for selected physicians serving the Latino Community.

#### **Target Population:**

Elementary school aged Latino asthmatics and their families in Los Angeles.

#### **Short and Long Term Implications:**

The short term implications of this project are to improve the asthma management of Latino children with asthma living in the Los Angeles area. This improved asthma management will be reflected in decreased utilization of the emergency room for asthma treatment, more



effective use of asthma medications, and an enhanced sense of self-efficacy among both the asthmatics and their families in their ability to manage the child's asthma.

The long term implications are the creation of a community-based asthma self-management program which can be used in Latino communities around the country.

### **1993 and 1994 Accomplishments:**

The recent accomplishments include the completion of the development of the study protocol. Preliminary work has been completed to begin implementation of this protocol in two additional cities: Chicago and Dallas.

### **Upcoming Events:**

In the immediate future the protocol will begin evaluation in three separate cities: Los Angeles, Chicago, and Dallas.

## **NATIONAL COOPERATIVE INNER CITY ASTHMA STUDY (NCICAS)**

### **PRINCIPAL INVESTIGATORS**

Ellen Crain, Albert Einstein School of Medicine, New York, NY

Peyton Eggleston, The Johns Hopkins University, Baltimore, MD

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Carolyn Kersmar, Case Western Reserve University, Cleveland, OH

Fred Leickly, Henry Ford Hospital, Detroit, MI

Floyd Malveaux, Howard University, Washington, D.C.

James Wedner, Washington University, St. Louis MO.

### **Objectives of the Project:**

The objectives of NCICAS are two fold. Phase I will identify intervenable risk factors determining asthma severity and morbidity among inner-city children. Phase II will develop and intervention based on these risk factors to reduce the severity and morbidity of asthma among these children.

### **Target Population:**

Asthmatics ages 4-9 living in census tracts with >40% of the residents below the poverty line.



### **Short and Long Term Implications:**

The short term implications of this project are to improve the asthma management of African American and Latino children with asthma at these eight sites. This improved asthma management will be reflected in a decrease in the number of days with asthma symptoms for these children. This improvement will be accomplished with the use of a case manager who will aid the asthmatic and his/her family in a number of different ways from environment controls, to increased adherence to medications, to more effective communication with their health care providers.

The long term implications are the creation of a clinic-based asthma intervention program which can be used in African American and Latino communities around the country.

### **1993 and 1994 Accomplishments:**

The recent accomplishments include the completion of the first phase of NCICAS. Important results from phase I of NCICAS include:

1. Culturally appropriate questionnaires have been developed to measure asthma morbidity and compliance with asthma therapy in an inner-city population. Important components of the questionnaire include sections on asthma responsibility (who takes care of the child's asthma) and patient management vignettes (how well the asthma is managed).
2. It is important to measure the magnitude of allergen exposure because such exposure is a major risk factor for asthma. Procedures have been developed and tested to (a) obtain access to the homes of inner-city residents, and (b) measure allergen levels in appropriate rooms of the home.
3. Doctor-patient communication is essential to ensure optimal patient adherence to medical instructions. While physician communication with inner-city patients has been assumed to be poor, it has not previously been possible to assess the quality of interaction. An innovative approach to studying doctor-patient communication and adherence to medical therapy has been developed for NCICAS. This approach is to record the visit on audiotape, and then to utilize a newly developed coding scheme which provides a quantitative evaluation of the quality of the interaction. A specially designed followup will monitor adherence. The techniques developed for NCICAS will provide valuable insights for a variety of diseases.







**The Partnership for Minority Access to Doctoral Degrees (PMADD)  
An M.S./Ph.D. Bridges to the Future Program  
at  
The University of North Carolina**

**Henry Dearman, Ph.D.  
Program Director  
University of North Carolina at Chapel Hill**

**Overview:**

Biomedical sciences suffer from a severe underrepresentation of minority doctorates. To aid in resolving this disparity and encourage greater numbers of underrepresented students, e.g., African American and Native American, to pursue doctoral degrees, a collaboration among four institutions in the University of North Carolina System was established. This collaboration is called The Partnership for Minority Access to Doctoral Degrees (PMADD). The Partnership includes the University of North Carolina at Chapel Hill (UNC-CH) and the historically minority universities (HMU), North Carolina A&T State University (NC A&T), North Carolina Central University (NCCU), and Pembroke State University (PSU). PMADD provides graduate training and resources directly to the underrepresented populations within our university system through a single admission MS/PhD program: the MS earned at the HMUs and PhD at UNC-CH. In addition, the Partnership recruits students nationwide. Undergraduates just beginning to realize their academic potential in science are principal targets. Currently there are seven students enrolled in PMADD. Six are at the M.S. level and one is now a Ph.D. student.

Faculty are a critical component of PMADD. PMADD faculty administer the Partnership and provide sustained mentoring and advising throughout. Interinstitutional course registration, already a reality for the participating institutions, will be used to provide breadth and depth of science content and begin to familiarize the students with the UNC-CH culture. The Partnership fosters the utilization by MS students and their A&T and NCCU faculty mentors utilize research resources of UNC-CH such as faculty, technical facilities, and instructional workshops. Concurrently, UNC-CH research faculty visits A&T and NCCU to conduct seminars and workshops. This multifaceted interactive approach will ensure ongoing communication and exposure between the MS students and the doctoral granting institution and also promote meaningful communication between the faculty of all four institutions.

Since Native American students are greatly underrepresented in doctoral programs, PSU, the state's historically Native American university, is a unique, essential member of the Partnership. Although PSU does not offer MS degrees in the sciences, it does have a NIH-funded MARC program that begins training undergraduates for research careers. Therefore,



PSU has a growing pool of potential Native American applicants for the MS/PhD program and currently there is a PSU student enrolled in PMADD.

With this Partnership, the success of underrepresented students in biomedical research careers will be facilitated by a process of advancement that has academic and personal support as its cornerstones. Our experience with innovative educational programs at UNC-CH tells us that the holistic educational approach is the key element for the scientific success of these individuals.

**Purpose:**

The rationale for sustaining and strengthening the partnership between three historically minority institutions, NCA&T, NCCU and PSU, and UNC-CH is compelling. All are member institutions of the University of North Carolina System and all are in close geographical proximity. The three historically minority institutions have well established NIH-funded MARC and/or MBRS programs indicating their competitiveness and commitment to recruiting undergraduates to biomedical careers. Two of the partner institutions have significant extramurally funded research programs. NC A&T attracted \$18.7 million sponsored program funds in '92-93. UNC-CH is a major biomedical research center and its faculty attracted \$221 million in external funds in '92-93.

The educational partnership in the sciences began in earnest in the early 1980s after extensive discussions dating to the late 1970s. These close relationships established the background upon which the current program is based. The first formal graduate education agreement was established in 1984 when NCCU and UNC-CH offered a joint MS/PhD degree program in biology, chemistry and psychology. Participating students registered simultaneously in both Graduate Schools (NCCU for the MS and UNC-CH for the Ph.D). While limited in success due to funding constraints at NCCU, this program did permit the establishment of close working relationships between the two institutions.

NC A&T and UNC-CH have had numerous interactions pertaining to the establishment of joint graduate programs. Moreover, many A&T students have participated, and will participate in 1994, in the summer in the UNC-CH Summer Pre-Graduate Research Experience. PSU and NCCU students also participate in this research program. This summer program provides an intensive undergraduate research experience that has been enormously successful in attracting minority students into biomedical careers through introducing them early to "cutting edge" research. While this program attracts minority students nationwide, a significant number are from the partner institutions.



## **Progress:**

Given the short time that PMADD has been in existence, we feel that it has been quite successful. In summary, the PMADD progress since its inception 18 months ago is as follows:

- \* Successfully enrolled and funded seven students in PMADD, four from NCCU and one from NC A&T.
- \* Supported one student through successful completion of the master's degree and welcomed her at UNC-CH for continuation of her doctoral program.
- \* Brought one student from Pembroke State University into the program.
- \* Gathered faculty and students from all participating institutions for two PMADD conferences (one at NCCU and one at UNC-CH) designed to deepen commitment to PMADD cooperation and explore further avenues for the development of the program.
- \* Generated growing enthusiasm for student and faculty participation in PMADD among the participating universities and at other HBCU's where recruitment efforts have been strong and aggressive.

## **General Overview of Progress:**

**Criteria for participation:** Given the unique array of support offered to PMADD student participants, criteria for determining admission differ from those accorded students applying independently directly to master's and doctoral programs at UNC-CH from their undergraduate institution or from their master's institution. The primary and first selection of PMADD applicants is made at and by the master's institution (HBCU) where applicants are counseled about their career goals, aptitude and skills, the goals and purposes of PMADD and the application process. These candidates are encouraged to apply for inclusion in PMADD and their applications are evaluated and ranked by PMADD directors at the masters institutions. The **second** and final determination of PMADD participation is made at UNC-CH by the Ph.D. department to which the student is applying. This determination is made by departmental faculty after on-site interviews and, at times, previous laboratory or research experiences by the students at UNC-CH with the likely assurance that the student will succeed toward a timely completion of their doctoral work.

**Students and Faculty participating in PMADD:** Each of the **five PMADD Fellows** supported during the program's first year have been served by a **faculty advisor directly at the master's campus** and **one faculty advisor/contact at UNC-CH**. PMADD Fellows have integrated themselves into their home departments and faculty at the master's institutions and most have had research, course or advisory contact with additional faculty at UNC-CH during their master's programs [or in at least one case, our student from Pembroke State University,



during his undergraduate program via the UNC-CH Summer Pre-Graduate Research Experience (SPGRE)]. As PMADD Fellows continue in their programs, it is anticipated these relationships will mature and multiply.

**Specific activities and outcomes:** By the end of the first year of PMADD, all participants have moved forward with their master's program. Throughout the year faculty and campus directors have been in regular contact in order to negotiate the practicalities of the program, deepen and expand the mission and goals of PMADD, encourage more regular cooperation and faculty/student exchanges between the schools and plan for future modifications of the program.

Student's transferred to doctoral program: One student has successfully defended her master's thesis at NCCU and completed all requirements for the Master of Science degree. She has swiftly moved directly into the doctoral program at UNC-CH with faculty at Chapel Hill who had worked with her and NCCU faculty during her master's program.

### **Program Implications:**

The implications of PMADD are profound. The foremost implication is, of course, the clear potential for increasing the number of underrepresented minorities, particularly African Americans and American Indians, attaining Ph.D. degrees in the biomedical sciences. Moreover, the presence of PMADD at the master's granting institutions is expected to enhance the recruitment and enrollment of master's degree seeking students. Many of whom are likely be encouraged to pursue doctoral studies. Additional implications are the academic agreements and research cooperations between the four partner institutions. This will be observed in the team building activities that involve the faculty from the partner institutions. Joint activities in educating and providing research experiences for PMADD students is expected to be the catalyst for many collaborative activities involving the faculty.



**Minority Youth Health Behavior Research:  
The Development and Evaluation of Interventions**

**Brian Flay, M.D.**  
**Director, Prevention Research Center**  
**University of Illinois at Chicago**

The National Institutes of Health, Office of Research on Minority Health (ORMH) is funding seven organizations to develop, implement and evaluate coordinated programs of community based health behavior interventions to lower the unacceptably high rates of morbidity and mortality among minority youth.

**Background:**

This project originated with Congressional concern over the health of minority youth. NIH, under the guidance of the Office of Research on Minority Health, convened a working group to develop a proposal to address the issue. ORMH allocated \$25 million dollars over 5 years to fund these studies.

The seven intervention investigators, their organizations (and their intervention sites) are as follows:

John B. Bolland, University of Alabama (Huntsville)

Dorothy C. Browne, University of North Carolina at Chapel Hill (North Carolina)

Richard F. Catalano, University of Washington (Seattle)

Betty A. Chewning, University of Wisconsin (Wisconsin American-Indian Tribes)

Brian R. Flay, University of Illinois at Chicago (Chicago)

John B. Jemmott, Princeton University (New Jersey)

Lydia N. O'Donnell, Education Development Center, Boston (New York City)

An eighth site, a data center (Tyler Hartwell, Research Triangle Institute), will maintain data quality across sites.

**Substance:**

The projects focus on strategies for decreasing violence-related injuries and deaths, sexually transmitted diseases (STDs) and unwanted or unintended pregnancies in minority youth ages 10-18. Several of the projects will also assist young people in developing resistance to the use of alcohol and other drugs. Each project is different, as a requirement for funding was that the project be designed with significant community input and be demonstrably sensitive to the needs and concerns of that community. It was felt that while this constraint makes cross-site comparison complex, it facilitates the acceptance and efficacy of the projects.



In addition to their excellent scientific merit, the grants provide an interesting geographic range, and target Black, Native American, Asian and Hispanic youth. Three (Alabama, Seattle, Princeton) will work exclusively with a wide range of neighborhood or community organizations and the other four will provide at least some of the programs in local schools. A few of these projects represent collaboration between minority and majority institutions, and all included community-based organizations in the design of the projects. All will have community participation throughout the implementation phases, in both advisory and decision-making capacities.

Recognizing that it is important to teach skills as well as to impart information in order to change behavior, the interventions all teach skills, though the content varies across sites. Interventions will help young people develop and practice skills in decision making, problem solving, anger management, communication, conflict resolution, and reducing their own risks of unhealthy outcomes. The young people will learn to identify and use community resources which exist to support positive alternatives. They will be helped to develop control over their own impulses and to understand and combat peer and media pressure to engage in unhealthy behaviors.

The interventions will be delivered in a variety of innovative ways -- through small group exercises, discussions, cooperative learning projects, role playing and skill training, as well as through films, videos and, in some cases, specially designed computer games. One group's approach (Huntsville) is that there is something about certain neighborhoods which creates a wall blocking out health promotion efforts, and that in order to see any public health impact, that "wall" has to be knocked down. So their first steps are to map and eliminate the wall.

Companion interventions will be offered to parents at several of the projects. The various interventions will be evaluated carefully and compared across sites.

### **Process:**

The steering committee, consisting of the Principal Investigators of each project and the NIH Project Coordinator, has met five times. Dr. Dorothy Browne, the PI from North Carolina, is the chair of the steering committee, and Dr. Richard Catalano, of UW Seattle, is vice chair. The group has excellent working relationships. A policy and procedures manual was agreed upon, Flay including a committee structure and publications policies. Steering committee and other meetings have been held at several of the sites, enabling the site's staff to attend and understand the whole project.

A measurement working group undertook the time-sensitive effort to develop a common core baseline questionnaire to be used at each site. That task has been completed, and several of the projects have begun data collection. The working group will continue to monitor measurement issues, and to assist in the development of questions which may be used by two



or more but not all of the sites as they specifically measure theoretical constructs of particular interest. The group will have input as reports and articles are developed and written.

An intervention working group is looking at commonalities across interventions and intervention designs and theories. Since each site has a specific and different design and approach, this is an exceptionally complex undertaking. This group has discussed all aspects of intervention, have shared curricula and designs, and have cross-trained intervention specialists. For example, two of the health educators on the Chicago project went to the Princeton project to assist in training of the intervention staff there.

Two of the projects have been awarded minority supplements, Chicago for an African-American predoctoral student, and Wisconsin for a Native-American faculty member. Dr. O'Donnell's group, EDC, has been awarded an NINR grant to work in a companion school to the ones for this project, amplifying its reach. Investigators from the Chicago and Princeton groups are developing a proposal to test the relative efficacy of "culturally sensitive" versus "Afro-centric" approaches to program delivery.

### **Findings:**

There are no findings yet, as the projects are just getting underway. Indeed, it will be several years before there are meaningful results available from these studies. However, we have presented information about the projects at the 1993 meetings of the American Public Health Association and the American Psychological Association. Local press coverage to date has been uniformly positive. We expect that first publications will cover issues of community acceptance and project development, and that subsequent articles will deal with baseline data. Longitudinal findings and cross-site comparisons are planned at later dates. Several journals have expressed interest in publishing a group of papers, and the Steering Committee is considering publishing at least one book on the projects.

This project is a joy to work on. Watching the various sites develop and interact, planning and participating in the meetings, and talking about it with interested individuals continues to be fascinating and exciting work. The sharing that has occurred at these meetings continues to enhance the quality and value of each individual project. In addition, each site reports that the involvement of community representatives in planning interventions has enriched them, enhanced their acceptability, and hopefully has improved their effectiveness. These projects have the potential to provide very helpful and important information and guidance for policy and program both in this country and elsewhere. They will also help the people who are participating in the interventions, and train new social and behavioral science researchers.



### **Mid-west Region Project Descriptions:**

We now provide more information about the three projects that are in the mid-west region -- Alabama, Wisconsin, and Chicago.

The Huntsville Alabama project has a team that includes a political scientist, counselors, physicians, and staff from community organizations, including a food bank and a county health department. This project addresses the issues in an innovative fashion. Three assumptions underlie their project. First, health promotion efforts targeted toward inner city neighborhoods have often been unsuccessful because they fail to address the special needs and circumstances of residents, which may not mesh with those of the service providers. Second, a sense of community can be built, by empowering residents to take control of their lives and surroundings, working on issues of primary importance to them. Third, a community, once empowered, is better able to address other issues, including health issues. This intervention, to be conducted in three housing developments in Huntsville Alabama, will address the problems of youth violence and the harmful sequelae of sexual activity in youth by working with communities in the three-step process outlined above. Their target audience will be all of the young people aged 10-24 in the housing projects, but their community empowerment model will work with parents and community leaders as well. (Dr. John Bolland, ISSR, University of Alabama, Box 870216, Tuscaloosa AL 35487-09216, 305/348-3821)

The northern Wisconsin project is headed by an educational psychologist, and will work with the Great Lakes Intertribal Council on a project designed to reach youth in the 11 Native American tribes and bands in Wisconsin and Michigan. Their programs will incorporate existing curricula and programs respected by the tribes along with new resources to strengthen the cultural framework within which the young people live. They will be working in the schools and in the health clinics which serve the population. A "Peacemakers' Program", a "Trails" program and a series of programs which involve respected tribal elders will be components of the interventions. Building on previous research, the researchers argue that they must integrate and collaborate with other programs, not simply start anew. One goal of the intervention will be to increase adolescents' commitment to and belief in their educational and career options, as a form of primary prevention of health damaging behavior. As the target audiences are spread out over a wide geographic area, innovative video and computer programs will be used to enhance and extend the reach of the interventions. These researchers point out that alcohol abuse and suicide are disproportionately prevalent in Native American youth, so the interventions will target these behaviors as well the prevention of other types of violence, STD and unintended pregnancy. (Dr. Betty Chewning, Sonderegger Research Center, University of Washington, 425 N. Charter St., Madison WI 53706, 608/263-4878)

In Chicago, a social psychologist leads a multidisciplinary and multi-ethnic team of experts from the Prevention Research Center (in the School of Public Health), the department of



African-American studies, and the colleges of nursing and medicine at the University of Illinois. They have designed a complex series of interventions to be delivered to grade 5-7 students in elementary schools in inner city and suburban Chicago. One set of interventions will focus on enhancing the social and personal skills of students in the classroom setting. The second will enhance the classroom work by involving parents, the school community and the neighborhood in a single integrated program. The researchers argue that other programs have not demonstrated success partly because they are "too little, too scattered, and too infrequent," they are not developmentally appropriate, and they deal only with the individual, not with the setting. This multifaceted intervention will avoid these pitfalls. A comparison group will receive a health enhancing curriculum which will not deal with violence and STDs, but will focus on health-enhancing behaviors such as nutrition and fitness. The research team will deliver the interventions to students in the 1994-95 5th graders and follow those students through 7th grade. They will train teachers to deliver it to youth in subsequent cohorts. This promises to embed the interventions in the schools age 6 in an ongoing fashion. (Dr. Brian Flay, Prevention Research Center, University of Illinois, 850 W. Jackson Blvd, suite 400, Chicago IL 60607, 312/966-7222)







## **Brain MRSI and SPECT Changes in Cocaine and Alcohol Abuse**

**Joseph Frascella, Ph.D.**

**Neurosciences Research Branch, Division of Basic Research  
National Institute of Drug Abuse**

### **Overview:**

Recent research has revealed that cerebral damage occurs in cocaine abusers. Additionally, concurrent abuse of cocaine and alcohol is highly prevalent, and this combination has been shown to increase the risk of toxicity and lethality. While there is no evidence to suggest racial differences in MRSI-detected phosphorous compounds, this topic is not well studied. Given the reported differences in the incidence of cardio- and cerebro-vascular disease (e.g., hypertension (60-62) and stroke (63, 64) between subjects of Caucasian and African ancestry, it is possible that racial vulnerabilities to cerebro-vascular insults may be a factor mediating the effects of cocaine abuse on cerebral phospholipids and phospholipid metabolites. This study will address this issue.

### **Significance and Rationale:**

This investigation will characterize the pattern and time course of cocaine-related cerebral damage in male and female African-American populations age 30-45. This information will help determine if brain changes in these populations observed help determine if brain changes in these populations observed by MSRI and SPECT techniques in cocaine abusers represent: (a) transient phenomena, (b) more long-term diminished cell function, or (c) loss of neuronal tissue. Understanding the neurobiological mechanisms underlying this impairment is important for the assessment and treatment of cocaine-addicted individuals. Objective neurobiological markers of brain impairment are important because actual performance on neurocognitive testing might be significantly affected by patient motivation and affective status. Moreover, objective neurobiological makers also might help in tracking the efficacy of interventions designed to arrest or reverse brain damage secondary to cocaine abuse. Such markers might also facilitate early detection of brain involvement (possible before cognitive function is affected), which could be important for the implementation of aggressive biological and psychosocial interventions.

### **Goals and Design:**

The primary goals of this research investigation are to study the cerebral metabolic, neuronal, and blood flow effects of chornic cocaine abuse, to compare and contrast these effects with those of alcohol abuse. The secondary goals are to determine if these cerebral metabolic,



neuronal, and blood flow effects are transient or relatively permanent, as well as to determine whether these effects differ in males and females.

To accomplish these goals, both MRSI SPECT, and MR imaging techniques will be used to study four groups of age- (30-45 years of age) and education-matched African-American subjects: cocaine-only abusers, alcohol-only abusers, cocaine and alcohol abusers, and non-substance abusing controls. Each sample will consist of half males and half females to enable comparison of African-American men and women. The study is a substance abuse (cocaine-only abuse vs. cocaine and alcohol abuse vs. alcohol-only abuse vs. no substance abuse) by gender full-crossed design. Fifteen subjects will be recruited from residential and outpatient treatment programs in the San Francisco Bay area. Normal control subjects will be recruited from community groups and churches in the neighborhoods that feed the residential treatment programs. The subjects will be studied during "Early Abstinence" (the fifth week after cessation of drug use) and during "Late Abstinence" (6 months after cessation of drug use) to determine whether observed effects of substance abuse are transient or relatively permanent.



## **Study of Hemochromatosis in Africans and African Americans**

**Richard Klausner, M.D.,  
Chief, Cell Biology and Metabolism  
Division of Intramural Research  
National Institute of Child Health and Human Development**

Iron overload represents a devastating clinical problem in a variety of circumstances. In the Caucasian population, a gene linked to the HLA locus on chromosome 6 is responsible for abnormal regulation of dietary iron uptake resulting in progressive iron overload and the disease referred to as hereditary hemochromatosis. If untreated, this disease results in severe organ damage and death. As many as one out of seven to one out of nine Caucasians carry the hemochromatosis gene which is expressed as an autosomal recessive trait. Other causes of iron overload include syndromes of ineffective erythropoiesis, such as thalassemia, and multiple transfusions.

Iron overload was first described as a syndrome prevalent among the Bantu population in South Africa in the early part of this century. While exact clinical descriptions of the sequelae of iron overload in this population are incomplete, evidence has accrued that throughout sub-Saharan Africa, a common syndrome of iron overload is indeed associated with significant clinical problems including liver failure. The early observations in South Africa correctly linked the iron overload syndrome with dietary iron excess that primarily resulted from the ingestion of traditional beers brewed in iron pots. The extremely high and very bio-available iron in these brews is clearly an essential component in the iron overload. Recently, more extensive analysis in Zambia, Swaziland, Malawi, and Zimbabwe has confirmed the high prevalence of iron overload in up to 15% of the adult population. While the previously recognized role of the ingestion of iron-rich traditional beer was reconfirmed, the observation that siblings who had ingested the same brews to apparently similar extent often demonstrated striking disparities in iron accumulation, and the identification of individuals with apparently identical iron overload syndromes but in whom there was no historical evidence for beer ingestion, suggested that there was, in addition to the environmental stress, a genetic predisposition to iron overload.

In a study of 36 families in Africa involving relatives of biopsy-proven iron overload, directed by Dr. Victor Gordeuk, data was presented that supported the possibility that a single gene was contributory to the development of iron overload in the face of enhanced iron ingestion. A model for an iron overload disease, referred to as African Hemochromatosis, was thereby formulated. According to this model, individuals who drank large amounts of iron-laden beer but who lacked even a single copy of the proposed iron loading gene failed to get a clinical syndrome of iron overload. In individuals that had a single copy of the proposed gene (heterozygotes), the drinking of beer presented an iron stress that resulted in



iron overload. In other words, the combination of a single copy of the gene and excess iron ingestion resulted in an apparently autosomal dominant trait. In patients with two copies of the proposed iron loading gene, iron overload syndrome would occur in the absence beer drinking, and the disease would appear as an autosomal recessive disorder. While this initial study presented data consistent with this hypothesis, the data was quite preliminary and required much more information in order to provide definitive proof for or against the existence in the African population of an iron overloading gene.

In order to approach afresh the question of a genetic component in African iron overload, we have established a study based in Zimbabwe in collaboration with the Department of Medicine of the University of Zimbabwe Medical School in Harare. This study utilized the identification of biopsy-proven index cases in order to analyze the extended pedigrees in an attempt to map the clinical syndrome of iron overload in relatives of affected individuals. The study involves three components. First, after the identification of an index case and review of the liver biopsy specimen, a team visits the village where the affected individual lives. We have chosen to study rural, village populations because of the stability of the social structure and the general ability to locate all family members within the same village. The collection team spends at least three days in each village taking extensive histories and drawing blood samples for analysis in Africa. These blood samples are transported to a laboratory that has been established at the University of Zimbabwe Medical School in Harare where the desired clinical tests are performed and all of the data and additional blood samples are sent to the Cell Biology and Metabolism Branch in the Intramural Research Program at the NIH. The blood samples are used to establish immortalized cell lines for future analysis of DNA and the data is analyzed. Up to this point we have successfully established a working infrastructure in Africa, have begun to identify affected pedigrees, and are beginning to collect data from throughout Zimbabwe as well as in Swaziland.



## **Research Centers in Minority Institutions Program**

### **Research Infrastructure for Environmental Health Science Research at RCMI-Eligible Institutions**

**Sidney A McNairy, Jr., Ph.D.**  
**Program Director**  
**National Center for Research Resources**

#### **Background on Issue:**

In order to facilitate the participation of Research Centers in Minority Institutions (RCMI)-eligible institutions in environmental health science/ toxicology (EHS/T) research, a planning meeting was held in April, 1991. The long-range objective was to establish and develop institutional capacity to understand and prevent environmentally-induced diseases, especially those that have a disproportionate impact on minority populations. After this meeting, six of the RCMI grantees submitted supplemental EHS/T applications; three meritorious applications were funded. Two of these, the Ponce School of Medicine in Puerto Rico and Clark Atlanta University in Georgia, have been supported through cofunding from the Office of Research on Minority Health since October 1, 1993. The other is supported via the National Center for Research Resources appropriation for the RCMI Program.

#### **Collaborative Goals with the Office of Research on Minority Health:**

The goal is to work collaboratively in achieving the objectives of the RCMI Program, i.e., "to expand the National capability for research in the health sciences by assisting, through grant support, predominantly minority institutions that award doctorates in the health professions and/or health-related sciences to strengthen their research environments. The primary goal is to enable these institutions to become more competitive in obtaining support for the conduct of biomedical and/or behavioral research relevant to the mission of the Public Health Service." A spinoff benefit of this enhanced research capacity in EHS/T is the development of minority biomedical scientists in this area.

#### **Target Population:**

Puerto Ricans (Ponce School of Medicine)  
African Americans (Clark Atlanta University)

#### **Program Description and Objectives:**

At the Ponce School of Medicine the objectives are to expand their EHS/T program through faculty expansion, acquisition of state-of-the-art equipment, and initiation of four pilot



research projects which include studies of hazardous trace elements in drinking water in Puerto Rico and mechanisms of action of ciguatoxins. The level of trace elements in drinking water obtained directly from houses from all major urbanizations in the Ponce area and the drinking water sources (wells and storage reservoirs) will be analyzed using ICP-emission spectroscopy. Lead will be the major element of interest; however, As, Cd, Cr, Hg, Mn, Se, and Zn will also be examined. From the data obtained from different households that supply the drinking water samples, correlations between general health, academic performance, and trace-element concentrations will be determined. Analysis of trace-metal content of other types of samples will supplement existing drinking water data to provide additional information regarding the probability of inhabitant low-level trace-metal poisoning. Specifically, blood samples from dogs entering the Biomedical Research Facility will be screened for lead levels. In addition, human, adult and child, blood samples will be examined for lead and other hazardous trace elements. The composite data collected in these studies are intended to indicate the likelihood that a significant number of inhabitants are being exposed to elevated levels of trace-metal. The data are also intended to identify a potential target group for future epidemiological study examining the correlation between low level trace-element exposure and health-related effects. Future projects will evaluate the drinking water of other cities in Puerto Rico. As a part of the infrastructure development, scientists at the Ponce School of Medicine will assess the value of using human cells for analyzing the genotoxicity of ciguatoxin(s). Until now, this has not been studied in detail. It is anticipated that data emanating from these studies will be more relevant to human health. Ciguatera fish poisoning is now recognized as a human health problem in Puerto Rico and all tropical areas where marine fish represents a significant source of food.

The goal at Clark Atlanta University is to expand the on-going research efforts in EHS/T. This is being accomplished by developing the infrastructure necessary to support this type of research, thereby increasing research productivity. The infrastructure development includes enhancement of GC/MS capability, the establishment of a cell culture facility, addition of a computer workstation in the NMR facility, enhancement of informational resources in the environmental health sciences, increase in research manpower by providing small grants to fund new collaborative research projects in this area and allowing current projects to be expanded further into this research area. These infrastructure improvements will serve to support the research interests of the current scientists in the "Chemical Modulation of Cellular Function" focus group.

### **Short and Long Term Implications:**

At both the Ponce School of Medicine and Clark Atlanta University the short-term implications are a more competitive research environment, with a focus on EHS/T. The long-term effect is the production of significant research findings that will help to assess and project the adverse impact of environmental pollutants on human health, especially minority populations. A spinoff benefit of the anticipated increase in research manpower and



development in the EHS/T area is increased opportunities for students to receive research training in laboratories dedicated to investigations of the health effects of environmental agents.

**Future Events:**

A principal measure of the effectiveness of the RCMI Program is the success of the grantee community in obtaining PHS support. Since 1984, the year before the initial RCMI awards, the PHS support obtained by the grantee community almost tripled by 1993. More specifically, the NIH support for AIDS and AIDS-related research increased from \$0.68 million in 1988 to \$14.06 million in 1994. This enhanced research infrastructure is enabling RCMI-eligible institutions to produce more minority biomedical researchers.

By developing the clinical research infrastructure at minority medical schools, and improving the biomedical research infrastructure at other minority institutions, many research questions germane to minority populations could be addressed more effectively. Additionally, the number of biomedical scientists, especially physician scientists, would be increased significantly.







## **Risk Determination and Epidemiology of Otitis Media**

**Jay Moskowitz, Ph.D.**

**Deputy Director and Acting Scientific Director  
National Institute on Deafness and Other Communication Disorders**

Otitis media is one of the most common diseases of childhood and is one of the major causes of hearing loss in children. Those minority children who lack health care and socioeconomic advantages are at increased risk for the infection and its sequelae. The National Institute on Deafness and Other Communication Disorders (NIDCD), as part of its mission, supports and conducts research that will improve understanding of the epidemiology and pathogenesis of otitis media and may ultimately lead to improved diagnosis and the development of prevention strategies and effective treatment for those who suffer from it. Through the sponsorship of the Office of Research on Minority Health (ORMH), NIDCD provides support for two major otitis media projects -- "Risk Determination of Otitis Media Chronicity" and "Epidemiology of Otitis Media: Prenatal, Infant and Environmental Factors." These two projects and a new "Partnership Program" that the NIDCD has initiated with academic centers which have large enrollments of underrepresented minorities to encourage their participation in fundamental and clinical research related to hearing, balance, smell, taste, voice, speech and language, will also be discussed, and recent progress will be presented.







## **Developmental Centers Program**

**Kenneth Olden, Ph.D.**

**Director**

**National Institute of Environmental Health Sciences**

### **The Issue:**

Most Americans want to live long and healthy lives, and the majority of them achieve that goal. In general, however, members of economically disadvantaged and/or underserved populations are less likely to do so. At every stage of life, these populations suffer disproportionate levels of morbidity and mortality. Additionally, they are most often the populations with the highest degree of exposure to environmental agents and are frequently the populations with the least information available as to the health consequences of exposure to these agents.

### **Research Strategy:**

The Developmental Centers Program is one aspect of a comprehensive initiative of the NIEHS in Environmental Equity. This program is the first step in establishing core centers that foster multidisciplinary research programs. They must utilize state-of-the-art science and address as a primary focus environmentally-related health problems of economically disadvantaged and/or underserved populations. Projects funded under this initiative are to carry out the developmental steps preceding a center application focused on this important public health issue. It is anticipated that successful applicants will have strong research capabilities and meaningful collaborative interactions with organizations/institutions representative of the affected communities.

### **Major Advances:**

This is a new initiative of the NIEHS. Currently, one project is already funded under this new initiative. This project is a cooperative effort between Tulane University and Xavier University. Four areas of research have been selected in which to conduct feasibility studies. They are 1) development of an exposure assessment tool to address elevated blood lead levels in African American children, 2) lead exposure and hypertension in African American children, 3) assessment of agricultural and municipal air pollution associated with pediatric respiratory disease and 4) community-based research on hazardous environmental chemical exposure in the Mississippi River delta region.



The program was recently re-announced and a second round of applications are under review. Two additional applications under this initiative will be funded starting April 1 bringing the total to three developmental centers.

**Significance:**

This program has attracted outstanding scientists to use their talents and cutting edge technologies to address the likely causal association between the disproportionate exposure to environmental agents and excess morbidity and mortality among the poor and ethnic minorities. The Tulane University/Xavier University grant represents the initial achievement of the Developmental Centers Program. This grant is to develop a multidisciplinary research program focusing on the effects of lead exposure on African American children, one of the most vexing health problems of socio-economically disadvantaged populations. The collaborative effort between the two universities that has resulted in the establishment of the Center for Bioenvironmental Research is a clear indication of the positive potential impact that this program will have on environmental equity. Furthermore, this collaborative effort between Tulane University and Xavier University, an historically black university, will strengthen the research capabilities of both institutions in this important area of investigation.

### **HEALTH EFFECTS OF LEAD IN PREGNANCY**

Many inner city houses and buildings where minority residents live contain lead-base paint. A major source of lead poisoning among children comes from direct ingestion of paint and dust that accumulates from the chipping and peeling of old paint from household surfaces. This exposure can also cause the development of lead storage in bone and other tissues in women and cause potential harm to future children through maternal exposure. Two projects are studying the potential exposures of the fetus to lead from maternal stores, attempting to learn if recent or historic exposures of the mother are most relevant.

### **BIOKINETICS OF LEAD IN HUMAN PREGNANCY**

The question of whether or not lead is mobilized from female skeletal stores during pregnancy and lactation has not been resolved. This project is designed to quantify if, when and how much lead is mobilized from maternal bone stores and transferred to the fetus during pregnancy compared to how much lead derives from the environment. In addition, the project also will address how remobilization of skeletal lead relates to bone turnover. Results of this study will have profound implications for both general community exposure to lead as well as occupational health, especially for women employed in the lead industry.

Phase I of this project demonstrated a stable lead isotope ratio ( $^{206}\text{Pb}/^{204}\text{Pb}$ ) in bone for long-term (i.e., > ten years) Australian residents. In Phase IA, the lead isotope ratios and lead content of blood and urine for 11 Eastern European immigrant females of child-bearing age



and one Australian control were measured monthly for two-six months. The blood lead (PbB) contents of the migrants measured soon after arrival in Sidney vary from 2.7 to approximately 20 mg/dl and the  $^{206}\text{Pb}/^{204}\text{Pb}$  ratios range from 17.62 to 18.36, compared with the Sidney control value of 16.78. As would be expected, there was an initial decrease in the  $^{206}\text{Pb}/^{204}\text{Pb}$  ratio in the migrants in the first month of the study. However, the isotopic ratios decrease to a plateau after three-five months and none reach the Australian base line. This plateau may indicate an equilibrium of blood lead with the mobile compartment(s) of skeletal lead. The differences in isotopic composition from the Australian values are twice that considered necessary to achieve positive outcomes for the experiment.

The decrease in  $^{206}\text{Pb}/^{204}\text{Pb}$  is of an exponential form and the rate appears to depend on blood lead content, being slower for subjects with higher PbB. Crowns of teeth in subjects of Eastern and Southern European extraction have isotopic values from 17.65 to 18.34, substantially different from the Australian base line. The isotopic data for teeth and biological samples demonstrate the suitability of the selected migrant groups for Phase II studies.

Phase II of this project will recruit recently arrived female immigrants of child bearing age from Eastern (and possibly Southern) European countries whose skeletal lead isotope profiles upon arrival are significantly different from the relatively uniform profiles found in the Australian population during Phase I. Their isotopic profiles will be characterized in blood and urine and in their environment. Isotopic changes during pregnancy and lactation will be monitored to determine how remobilization of lead relates to bone turnover. The results of this experiment will provide answers to the following questions:

- Is lead mobilized from the skeleton during pregnancy and lactation?
- When and how much lead is mobilized?
- At what rate does the isotopic profile of lead in blood equilibrate with that in the local environment in pregnant women compared with non-pregnant women of the same age with a similar prior history?
- What is the effect on the mothers' and infants' profiles from breast feeding or formula feeding during the first six months of postnatal life?
- Is there a relationship between lead mobilization and bone turnover?

### BIOKINETICS OF LEAD IN PRIMATE PREGNANCY

Mobilization of lead from female skeletal stores during pregnancy and lactation is being addressed. The overall objective of this study is to determine the mobilization of lead from



maternal bone stores during gestation and to quantify its placental transfer and incorporation into fetal tissues. Lead with an enriched stable isotope,  $^{204}\text{Pb}$ , is used to differentiate "recent" lead in circulation from endogenous lead which has accumulated in maternal bone.

To accomplish the study objective, the project has been divided into phases. The first phase called for the validation of methodology for analysis of stable Page 4 - Developmental Centers Program isotopes of  $^{204}\text{Pb}$ ,  $^{206}\text{Pb}$  and  $^{208}\text{Pb}$  as well as the development of methods, procedures and logistics, including X-ray fluorescence (XRF) measurements necessary to perform the subsequent phases. The current phase is designed to evaluate the transfer of environmental lead versus maternal body stores of lead to the fetus during gestation.

Transfer of lead from the mother to the infant during pregnancy has been well documented in experimental studies with various species including nonhuman primates. The requirements for an animal model of humans are especially complex if one is to quantitatively evaluate this transfer and compare the risk of long-term maternal lead stores with lead from the contemporaneous environment. A colony of cynomolgus monkeys that have had documented lead exposures since birth was identified and determined to be available to evaluate lead biokinetics in pregnancy.

Many of the experimental procedures used in the first phase were either new or had not been sufficiently validated elsewhere in the literature. A multidisciplinary approach was required with the application of a number of highly specific analytical methodologies. Among these are artificial insemination and ultrasonography, bone surgery and caesarean sections, ultra-clean room sampling and preparation of biological samples, thermal ionization mass spectrometry, low level flameless atomic absorption spectrophotometry, RIA and RRA assays for calciotropic hormones and a range of other pathology and clinical chemistry parameters.

The next phase of the study, using the chronically lead-exposed cynomolgus monkeys, will determine the relative quantities of lead mobilized from maternal bone and transferred to the fetus during pregnancy. Concurrently, the amount of lead incorporated into fetal tissues as a result of maternal exposure (via ingestion) during pregnancy will also be determined with the aim of constructing a biokinetic model for maternal/fetal lead transfer.



## **Lung Cancer in Black Americans**

**Kenneth Olden, Ph.D**

**Director**

**National Institute of Environmental Health Sciences**

### **Objectives:**

The incidence and mortality due to cancer is higher in African Americans than in any other racial group, although African Americans and other minorities have been historically underrepresented in research projects related to environmental carcinogenesis and cancer susceptibility. Environmental and genetic susceptibility factors that could play a role in African American cancer incidence have only recently begun to be addressed. For example, in the years 1986-87, the age-adjusted incidence rate of lung cancer in African American males was 50 percent higher than in Caucasian males. It is known that tobacco smoking is the major risk factor for lung cancer, accounting for approximately 80 percent of lung cancer cases. However, smoking alone cannot entirely explain the increased risk for lung cancer in African Americans, since there is no evidence that African Americans have a greater exposure to tobacco smoke, and the average number of cigarettes smoked per day is less than among Caucasians.

Socioeconomic factors, or exposure to environmental carcinogens in the diet, or from air or water pollution may play a role in the elevated lung cancer risk seen in African Americans. An important possibility with strong implications for public health intervention is that differences in susceptibility to the carcinogenic effects of tobacco smoke may partially explain why the risk of lung cancer varies among different races for a given amount of tobacco smoke exposure.

A new form of an important gene (called CYP1A1) has been discovered that is involved in the metabolism of certain carcinogenic components of tobacco smoke. This new gene structure or "genotype" was found in about 16 percent of healthy African Americans, but not detected in either Caucasians or Asians. It is not known if this genotype has any effect on the normal function of the gene. However, since a different variant form of this gene has been shown to be associated with increased lung cancer risk in Japanese, we want to test the hypothesis that this new African American specific genotype may be associated with the increased susceptibility to tobacco-induced lung cancer observed in African Americans.

**Target Population:** The target population for this study is African American lung cancer patients in three New York City hospitals: Bellevue Hospital, Sloan-Kettering, and Harlem Hospital. The distribution of the new genotype among a healthy population of African Americans from New York City, Pittsburgh, San Francisco, as well as a small sample from



Mali in West Africa is being studied as a control population. Persons of Caribbean descent, or with Spanish surnames have been excluded, and self-definition is used as the criterion for being African American.

**Short-Term and Long-Term Implications:** The implications of this research relate to the underlying cause of the high level of lung cancer in African Americans. Research is clearly needed in a number of areas in order to understand this phenomenon. The genetic susceptibility to tobacco that we are hypothesizing may be only one of many factors that is responsible. An important short-term implication of our research is simply that this is one of the few detailed research projects specifically focused on lung cancer mechanisms in African Americans.

It is important to stress that the genes being studied are closely linked to environmental exposure to carcinogens such as those found in cigarette smoke, and are not simply genetic susceptibility genes for cancer per se. This means that it is very unlikely that possession of this gene should have any effect on the health of non-smokers. However, if the presence of this new African American specific genotype does carry an increased risk for lung cancer in smokers, then some interesting and important potential public health interventions may be envisaged. For example, a screening program that identifies those carrying this (or other such) metabolic gene markers will allow health professionals to counsel such individuals that their risk for lung cancer if they smoke is even higher than it would be for the general smoking population. It is very likely that this would be a useful component in the campaign to decrease smoking, and thus have an impact on a number of adverse health effects in African Americans.

### **1993-94 Accomplishments:**

The frequency of the new genotype was determined in over 100 healthy African Americans by soliciting a small blood donation from volunteers. Sixteen percent of these individuals contained the new genotype. As expected, there was no influence of age or gender on the distribution of the genotype. Through collaboration, about 50 samples of DNA from African American patients suffering from sickle cell anemia were received. Interestingly the frequency of the genotype in these individuals was about 24 percent. Blood samples from healthy persons residing in Bamako, Mali, West Africa have been obtained. The new genotype was found to be present in 25 percent of the African samples analyzed so far. These results are consistent with the idea that the genotype originated in Africa.

To determine the role of the new genotype in African American lung cancer risk, the frequency of the occurrence of the genotype in lung cancer patients who smoke was compared to the frequency in the healthy population. From this comparison one can determine a statistical value called the "odds ratio." An odds ratio of two, for example, means that people having the genotype are twice as likely to develop lung cancer as a result



of smoking. To do this requires analyzing the genotype from a large number (about 200) of African American lung cancer cases, done via tissue specimens from patients who were seen in the three hospitals involved in the project. By isolating a very small amount of DNA from these stored, preserved tissue samples, and by using new techniques of molecular biology, the genotype in people with lung cancer can be detected even if they are no longer alive. This type of study is called a "case control" study, and the results of this study will tell us whether the new genotype is in fact an important contributory cause to the high rate of lung cancer among African Americans.

Methods for detecting the genotype from very small tissue samples have been optimized including histopathology slides used in cancer diagnoses for example. These methods are critical to this case control study. The first pilot phase was done in order to determine if it was worth continuing with a larger study. If the results had shown no difference between the lung cancer cases and controls, the study would not have been continued. Results from this small study showed an odds ratio of 2.4. This means that smoking African Americans who have the new genotype could have a 2.4 fold higher risk of developing lung cancer than would be seen for non-smokers. It is important to stress that this is a very preliminary result, based on a very small sample, and the results are not yet statistically significant. However, completion of the larger study will determine the validity of the implied results.

#### Future Plans:

Future plans are to complete the epidemiological study to determine whether or not the presence of this genotype in an individual has any effect on the risk for lung cancer related to smoking. The biological and biochemical significance of the new genotype in a small group of volunteer subjects will also be studied. For example, one possibility is that people with this form of the CYP1A1 gene might convert some of the compounds found in cigarette smoke into carcinogenic metabolites more readily. This could in turn lead to a higher level of exposure to the carcinogenic chemicals and a higher risk of lung cancer.







## **Exploratory Center Grants for Research on Health Promotion in Older Minority Populations**

**Thomas R. Prohaska, PhD**  
**Principal Investigator**  
**University of Illinois at Chicago**

The National Institute on Aging and the Office of Research on Minority Health recently established funding for six **Exploratory Centers For Research on Health Promotion in Minority Populations**. The Exploratory Centers are designed to conduct pilot research and plan for a program of medical, behavioral and social research, medical and psychosocial interventions, and programs of health education and community outreach aimed at improving the health status of older ethnic minority populations. The Center for Health Interventions with Minority Elderly (CHIME), at the University of Illinois at Chicago is one of these funded centers. The Center focuses on ameliorating health risks for minority older adults through modification of dietary intake, exercise, and other health practices. CHIME provides the opportunity for researchers with an interest in health promotion in older minority populations to develop projects, in close collaboration with the community, that will reduce health risk behaviors and promote and improve the health status of minority older adults. The Center for Health Interventions with Minority Elderly aims to: a) provide resources for conducting research on health promotion in minority older adults, b) stimulate and support new, high-quality multidisciplinary health promotion research on minority older adults, and c) facilitate dissemination of successful health promotion programs and products to community settings and wellness programs for application. The Center is comprised of community and academic advisory groups, core support groups, and research faculty. During the first three years, CHIME will conduct four developmental research projects. The four projects are:

1. Exercise Promotion of Minority Elderly in Senior Centers
2. Improving Exercise and Dietary Behaviors in Black Elders
3. Effects of Menopause and Health Promotion in Older Minority Women
4. Health Behaviors of Multiethnic Hispanic Elderly

Project One is a three year study designed to promote participation in exercise programs for African-Americans in senior centers. The objectives of year one are to obtain age and culture specific information on how older African-Americans view exercise including their beliefs about benefits and barriers of exercise, perceived support and encouragement to participate in exercise programs, and their perceived ability to participate. A series of focus groups is now in progress to examine these perceptions in men and women in one of three stages of exercise behavior: current exercisers, non-exercisers, and those who have recently participated in an exercise program but have since discontinued participation. Based on information obtained from the focus groups, year two will incorporate the more culturally appropriate information



into a health education intervention designed to increase participation and maintenance in an ongoing exercise program within senior centers. An evaluation of the success of the intervention will also be completed in year two. The third year examines program dissemination and maintenance. Three methods of training exercise program leaders to create and sustain exercise programs in the community will be investigated.

Project Two is a health education intervention to promote exercise and appropriate diet for older African-Americans with hypertension living in public housing. Focus groups are currently being conducted with older African-Americans who have hypertension in order to better understand their perceptions concerning exercise and diet in relation to high blood pressure. The focus groups include persons in one of three stages of hypertension treatment control: 1) those currently treating their hypertension including diet and exercise; 2) those with hypertension who are not exercising and are not on a controlled diet and do not plan to change in the near future and; 3) those older persons with hypertension who have recently participated in exercise behaviors and followed a recommended diet but have since discontinued. Information generated from the focus groups will be incorporated into a health education intervention for dietary and exercise behaviors for older African-Americans with hypertension. As with project One, this intervention will be evaluated in terms of participation and maintenance of the target behaviors.

Projects Three and Four are one year developmental projects. Project Three explores implementation of health promotion programs for management of the health consequences of menopause among minority women. Focus groups are currently being conducted with African-American and Latina women in four secommunity health centers. Several groups at each center will represent the several stages of health behavior change. Understanding of the menopausal transition, its health consequences, and the acceptability of various prevention interventions are the topics for the focus group discussions.

Project Four is a study to evaluate the lifestyle, health attitudes, perceptions and behaviors, social and health system factors, and cultural differences of urban, multiethnic Hispanic elderly as a first step in developing culturally-sensitive chronic disease interventions. A series of focus groups addressing different dimensions of culture, health and health behavior are currently being conducted separately among older Mexican, Puerto Rican and Cuban adults. The first series of focus groups identify health behaviors, attitudes, role of culture and values in health, lifestyle factors (diet, exercise, smoking, alcohol use, etc.), and perceptions of chronic disease. The second series will extend these concepts to the relationship of diet to obesity and chronic disease, dietary patterns and practices, and the role of family support in changing dietary behaviors. The third series address health services use and access, especially barriers to seeking preventive health care. Finally, the fourth series of focus groups will explore intervention approaches for health promotion, chronic disease prevention, preferred ways of learning, and recruitment and retention issues. This information can be used to



develop culturally-sensitive health promotion interventions which are tailored to the separate needs of these groups.

Taken together, the four projects represent a programmatic research approach to understanding health behaviors in minority older adults. The four projects have both unique and shared characteristics including: an emphasis on meaningful community sites; shared theoretical perspectives; common research questions, and an emphasis on development of age and culture specific information useful in facilitating appropriate health promotion activities.

CHIME is based on the principle that health promotion programs and activities work best when they are located within meaningful community sites where high concentrations of minority older adults are likely to be located (eg. senior centers, congregate meal sites, community health centers, and public housing). Along with the close connection to the community through the four individual projects, CHIME utilizes the resources and expertise of a Community Advisory Committee. The Community Advisory Committee fosters ties between the Center and older minority communities, and facilitates dissemination of new knowledge and community adoption of successful health promotion programs. The Community Advisory Committee provides guidance and direction to the Center. They advise research projects on issues of cultural relevance and recommend priority areas for research and community health promotion programs.

While CHIME is designed to be a research center for health promotion with minority populations, is also a resource for education and training of health professionals. Activities within the Center include education opportunities for students and faculty interested in health issues and health promotion with minority older adults. CHIME research projects and center activities also provide opportunities for training minority and non-minority students and health professionals on design and delivery of wellness programs for older minority populations.







## **Sickle Cell Disease Research**

**Clarice Reid, M.D.**  
**Chief, Sickle Cell Disease Branch**  
**Division of Blood Diseases and Resources**  
**National Heart, Lung, and Blood Institute**

Sickle cell disease, a worldwide health problem and is one of the most common inherited blood disorders. It affects a number of racial and ethnic groups including individuals from Africa, the Middle East, the Caribbean and South America, as well as people from Mediterranean countries such as Italy, Greece and Turkey. In this country, approximately one in 400 Black births will have sickle cell anemia, thus making it a significant public health problem.

Since 1972, the National Heart, Lung and Blood Institute, National Institutes of Health, has supported a broad based program of basic and clinical research and research training, with a national goal of reducing morbidity and mortality and improving the quality of life for patients with sickle cell disease and their families. Major advances over the past two decades have led to a greater understanding of the pathophysiology of this disorder at all levels. Although insights gained from basic research have been translated into improved patient care, the development of an effective treatment and/or cure for sickle cell disease remains elusive.

During this fiscal year, the Office of Research on Minority Health is providing support for three NHLBI sickle cell disease projects. The program objectives are: 1) to encourage and support the development of young minority investigators, 2) to support basic research leading to an improved understanding of the mechanisms of increased sickle cell-endothelial cell adhesion, and 3) to determine the risks/benefits of pre-operative transfusion requirements in patients with sickle cell disease undergoing surgery. A brief synopsis of these activities is provided below:

### **Training and Career Development:**

This project provides an opportunity for postdoctoral training of young minority investigators under the mentorship of a molecular biologist at the Meharry Medical College Comprehensive Sickle Cell Center. The sickle cell centers are ideal settings for career development and training of investigators in biomedical research. The spectrum of sickle cell research conducted through this mechanism follows from basic research to clinical application and the multidisciplinary approaches make it a very attractive environment for young scientists.



### **Basic Research:**

An outstanding and productive investigator at Rice University is examining abnormalities in sickle cell disease at the level of the erythrocyte and endothelial cell. This research combines rheological, biochemical and molecular techniques to study basic mechanisms of sickle-endothelial cell interactions, fluid shear alterations and damage of sickle cells. Understanding these abnormalities will permit a more rational approach to the design of therapies, as well as further elucidate the pathophysiology of the initiation of vaso-occlusion in sickle cell patients.

### **Clinical Research:**

The completion of analyses of data from the collaborative study examining issues related to transfusion therapy prior to surgery is supported in this project at the Sickle Cell Center, Children's Hospital at Oakland, CA. Transfusions are still considered the mainstay of treatment for patients with sickle cell disease. However, they are not without serious complications including iron overload, alloimmunization, transfusion reactions and the transmission of viral infections. Added to this problem is the lack of agreement within the practicing community about the management of blood requirements of patients with sickle cell disease prior to surgery. To clarify this issue, a collaborative clinical study was initiated within the Sickle Cell Centers to examine the outcome of patients undergoing surgery prepared with aggressive transfusion regimens as compared to those with simple transfusions. Preliminary findings suggest that patients are equally protected during surgery with either regimen and as expected patients with fewer transfusions pre-surgery developed fewer transfusion reactions and alloantibodies. If confirmed by the final data analyses, standards of care guidelines could be recommended leading to substantial cost savings by decreasing the length of pre-operative hospital stay currently required for exchange transfusions, as well as decreasing the costs of required blood products. This would be an extremely important public health outcome.



## **Research Supplements for Underrepresented Minorities**

**Anthony A. Rene, Ph.D.**  
**Assistant Director for Referral and Liaison**  
**National Institute of General Medical Sciences**

The National Institutes of Health (NIH) announced the Research Supplements for Underrepresented Minorities program on April 21, 1989. The program is intended to attract minorities into biomedical and behavioral research. Principal investigators holding NIH research grants are eligible to apply for supplements to their grants to support underrepresented minorities for research experiences in their laboratories. The supplements are awarded administratively by an NIH institute or center. The program provides the opportunity for an individual of an underrepresented minority group at any career level (high school to faculty) to pursue a research experience in a research intensive environment anywhere in the U.S.

The application process is straightforward. All that is required is the face page of form PHS 398, 3 to 4 pages describing the project and how the minority candidate will participate, budget pages, and a signed statement from the minority candidate addressing his/her career goals. A copy of the official transcript is required if the candidate is a student. There is no application deadline and the turn-around time is relatively short. The decision to fund a supplement may take as little as 6 to 8 weeks from the time of receipt. Although the success rate for awards varies among the institutes at the NIH, it is generally very high, 72 percent overall.

NIH grantees who are interested in this program should call their NIH program administrator to obtain a copy of the supplement guidelines and to discuss the application procedure. Eligible minority candidates should call (301) 594-7706 for information about the program. The most recent guidelines, published in the November 26, 1993 issue of the *NIH Guide to Grants and Contracts*, explain how to prepare an application and where to send it.







## **Systematic Lupus Erythematosus in Women and Minorities**

**Lawrence Shulman, M.D., Ph.D.**

**Director**

**National Institute of Arthritis and Musculoskeletal and Skin Diseases**

Lupus, more formally systemic lupus erythematosus or SLE, is a serious health problem that mainly affects young women. It is 9 times more frequent in women than in men. Moreover, it is one of the most common serious disorders of young women. Most women develop lupus first as teenagers or as young adults. People of all races may have lupus. However, lupus is 3 times more common in African-American women than in white women.

Lupus is a disease that can attack many different parts of the body. It may affect the joints, the skin, the kidneys, the lungs, the heart, or the brain. In most people only a few of these parts of the body are affected. Common signs of lupus are: red rash or color change on the face, painful or swollen joints, unexplained fever, chest pain with breathing, unusual loss of hair, pale or purple fingers or toes from cold or stress, sensitivity to the sun and low blood count. These signs are more important and helpful for diagnosis when they occur together.

In lupus, something is wrong with the body's immune system and this powerful system, which is usually protective, goes astray and attacks the body itself. We can think of the immune system as an army within the body with hundreds of soldiers (known as antibodies). They defend the body from attack by germs and viruses. However, the immune system sometimes becomes overactive and goes out of control. The antibodies attack healthy tissues in the body. This attack causes redness, pain, and swelling (inflammation) in certain parts of the body. This tendency for the immune system to become overactive may run in families.

We at the National Institute of Arthritis and Musculoskeletal and Skin Diseases lead the effort at NIH to find the cause of lupus, to bring better treatment for those with lupus, and ultimately find a cure or prevention. These are challenging tasks. Positive research findings are emerging from such diverse areas as immunology, genetic and environmental factors, hormone metabolism, epidemiology, and clinical trials. However, the cause of lupus is not yet known. It is possible that the disease may be initiated by a number of diverse factors.

It is now clear that lupus is much more common than it was thought to be 30 years ago. According to the Lupus Foundation of America, more than 500,000 people in the United States have lupus, and more than 50,000 new cases are diagnosed each year. While the overall prevalence rate is reported as 1 in 1,000, this rises to 1 in 245 for black women. For this reason, we at the NIAMS began a public campaign three years ago to educate young African-American women about lupus. We were aware that many in the African-American community have never heard of the disease, and it often goes undiagnosed until serious



complications arise. Lupus can be serious, but with early detection and good treatment, many people with lupus can lead normal and productive lives. To get this message out to the African-American community, I convened a Task Force on Lupus in High Risk Populations a few years ago. This group has helped us develop and disseminate materials for public education and a booklet, "What Black Women Should Know About Lupus." Over 100,000 of these booklets have been distributed. We are now completing a revision of the booklet and a communications kit, and will shortly begin a new public information campaign.

We have also been working hard to expand our research on lupus. Our current research support for lupus is now over \$17 million. On a clinical level, researchers at The Johns Hopkins Medical Institution in Baltimore, who have observed 185 lupus patients for 4 years, developed a disease activity scale that describes how often and in what ways flare-ups of the disease occur. This allows physicians to identify a flare-up in its early stages in order to start or increase treatment for the disease.

Our NIAMS intramural scientists have recently completed a 20 year follow-up study of patients with lupus nephritis to determine which of several new treatments was the most beneficial in delaying or preventing end-stage kidney disease, one of the most serious complications of lupus.

Our Multipurpose Arthritis and Musculoskeletal Diseases Centers have fostered many studies of lupus, including identifying strategies for reducing excess morbidity and mortality in blacks with lupus and setting up lupus disease registries to assess disease activity and pregnancy outcomes.

In the last two years NIAMS has sponsored scientific workshops and new research programs to foster new work on lupus. Our Caribbean Initiative Workshop brought together researchers from the Caribbean who work with distinct racial and ethnic populations at variable risk for lupus. We worked to develop new research initiatives for the study of lupus in these diverse populations. Another was the Antiphospholipid Antibody/Lupus Anticoagulant Workshop, held jointly with the National Heart, Lung and Blood Institute. These blood entities play a role in the coagulation abnormalities associated with lupus. Last, but not least, we held a highly successful Scientific Workshop to Develop a Future Research Agenda for Systemic Lupus Erythematosus. In this workshop we reviewed all the major research questions for lupus.

These workshops led to a major commitment last year to push the research agenda forward in a major way for lupus. We set aside new research dollars to target new and more research on lupus. We issued three different Requests for Applications. This was an enormous effort that would not have been possible without the help of the Office of Research on Minority Health. With Dr. John Ruffin's dedicated leadership to identify health research needs of minorities, systemic lupus erythematosus had been one are targeted as special interest for young adults.



The ORMH cosponsored with us a Request for Applications to study "Systemic Lupus Erythematosus in Women and Minorities." Twenty-four applications were received and reviewed. The two other Requests for Applications were for "Causal Mechanisms of Systemic Lupus Erythematosus" and "Specialized Centers of Research in Systemic Lupus Erythematosus."

We are very pleased with the three new research projects on lupus in women and minorities whose funding was initiated last year by the Office of Research on Minority Health.

One project is "A Genetic Association with Lupus in American Blacks," headed by John B. Harley, M.D., at the Oklahoma Medical Research Foundation. Dr. Harley seeks to identify the genetic basis for the high predisposition to lupus among African Americans. Based on preliminary data, a candidate gene encoding for a receptor (Fc receptor) found in polymorphonuclear leukocytes (PMNs) is being investigated. PMNs are cells capable of enveloping and destroying many substances. PMNs can engulf and digest the immune complexes that otherwise get deposited in organs such as the kidneys or skin of lupus patients. The research proposes that in lupus, because of a faulty Fc receptor, immune complexes are not readily cleared from the body and deposit instead in various organs inducing inflammation and tissue injury.

The second project is "Outcome of SLE in Minorities: Nature versus Nurture," headed by Graciela S. Alarcon, M.D., at the University of Alabama at Birmingham. Her research will examine the interaction of nature (immunogenetics) and nurture (socioeconomic factors) in the course and outcome of lupus. She will follow Caucasian, Hispanic, and African-American patients with lupus of five years or less duration at six month intervals over three years and note the frequency and severity of flares, disease activity, and severity. She will determine their immunogenetic genotypes, and record education level and occupation as a measure of socioeconomic factors. This study will provide important information on whether genetic or socioeconomic factors have greater influence on the severity of lupus.

The third project, "Using Idiotypes to Assess SLE Activity in Minority Women," is directed by Anne Davidson of Albert Einstein College of Medicine. She will examine the characteristics of certain antibodies that are pathogenic in patients with lupus. A special focus will be on the identification of antibodies associated with renal pathology in African-American and Hispanic patients with SLE using a series of newly developed reagents. Lupus nephritis is one of the more elusive and serious complications of SLE. Clarification of the pathogenic characteristics of certain antibodies may allow a targeted intervention for lupus patients with this life-threatening complication.

These projects promise to be important additions to our research base, expanding what we know about lupus, helping us find new ways of helping patients with lupus. The outlook for lupus patients has improved considerably. Forty years ago, only about half of all patients



with lupus were alive 4 years after they were first diagnosed with lupus. At present, almost all with lupus survive 5 years, and more than 8 in 10 survive 15 years. Our partnership with the Office of Research on Minority Health is very important to us as we strive to improve the outlook for lupus patients even more in the future.



## **Alcohol Prevention Aspects Among Mexican Americans**

**E. Taylor/E. Vanderveen, Ph.D.**

**National Institute on Alcohol Abuse and Alcoholism**

### **Purpose:**

This study identifies several components essential for the development of culturally appropriate preventive interventions that target Mexican Americans. Variables include gender variations, acculturation level, education level, income, drinking status, and migrational history. Specific objectives include the following:

- a. To identify the culture-specific attitudes, expectancies, and norms held by Mexican American regarding alcoholic beverage consumption in general, heavy drinking, and DUI.
- b. To identify optimal communication channels and resources for alcohol preventive information.
- c. To identify normative messages currently being presented in advertising for alcoholic beverages targeting Hispanics, and to measure the reactions of adult Hispanics to these messages.

### **Target population:**

Mexican Americans in California and Texas

### **Implications of Study:**

Findings from this research will be used to design culturally sensitive interventions to reduce alcohol abuse within the Mexican American population, guide decisions as to whether the intervention will be general for this population or tailored to specific subgroups within the population (e.g., separate interventions for men and women).







## **Minority High School Student Research Apprentice Program**

**Marjorie Tingle, Ph.D.**  
**Director, Biomedical Research Support Program**  
**National Center for Research Resources**

### **Goals and Objectives of the Program:**

The long range goal of the Minority High School Student Research Apprentice Program (MHSSRAP) is to increase the number of minorities in health-related research or the health professions. The program plays an integral part in piquing interest in science by providing minority high school students with up to eight weeks of hands-on experience in both basic and clinical laboratories. Over the past few years, the program has been modified to include a science teacher's component for in-service elementary, middle, junior and senior high school teachers, as well as for potential K-12 science teachers in pre-service education programs.

### **Target Population:**

Minority high school students, minority teachers or teachers who teach a significant number of minority students.

Each minority high school student received an apprenticeship slot which includes \$2,000 for their salary and the expenses for their research project. In 1993 MHSSRAP supported 250 minority students including African Americans, Hispanics, Native Americans and Pacific Islanders.







## **Cooperative Reproductive Medicine Network**

**Donna Vogel, M.D., Ph.D.**

**National Institute of Child Health and Human Development**

### **Background on Issue:**

The Reproductive Sciences Branch supports research on human fertility and infertility, and diseases and disorders of the human reproductive system. The area of reproductive health care has, in some instances, put into use diagnostic and therapeutic practices without sufficiently rigorous controlled evaluation of their effectiveness. An easily appreciated example is the diagnosis and treatment of infertility. Fervent desire to have a child, combined with the perception of a defect in such central attributes as their sexuality and fecundity, makes these couples vulnerable and highly suggestible. Uncontrolled, trial-and-error methods led to undeserved claims of effectiveness, and resulted in significant costs, both human and financial.

There is a greater need than ever to be able to identify reproductive disorders quickly and accurately, to describe subpopulations of infertility and subfertility, and to be able to provide the most appropriate therapies with the least possible delay. Therefore, in 1989, the NICHD issued a request for applications (RFA) for Cooperative Agreement applications to constitute a Network to carry out large, multicenter clinical trials in the areas of male and female infertility and reproductive diseases and disorders. The Network commenced operations in 1990.

### **Collaborative goals with the Office of Research on Minority Health:**

Network investigators have recognized that traditional recruitment techniques for clinical trial participants may not be efficient in reaching eligible minority subjects. An example is the site in Memphis, the population of which is 45% African American. Newspaper articles resulted in 355 phone calls; 167 were possibly eligible, 30 came for an interview and 5 entered the study. Only two of the interviewees were minority couples, and none entered.

Overall, one minority couple out of 57 total for Memphis was enrolled as of March, 1993. Therefore, this site applied for and was awarded an ORMH supplement to develop innovative methods to recruit minority couples to the study. Similar techniques had been used successfully by this team for recruitment of minority women for a study of nutrition in adolescent pregnancy.



### **Target Population:**

The supplement study will target infertile couples, particularly the female partner, who are members of minority groups in the Memphis metropolitan area.

### **Program Description and Objectives:**

[Network as a whole] There are a number of controversies in Reproductive Medicine which lend themselves to cooperative study. The objective of the Network program is to facilitate resolution of these problems by establishing a network of sites that, by rigorous patient evaluation using common protocols, can study large numbers of patients and can provide answers more rapidly than individual centers acting alone. Awardee institutions participate with the NICHD under a group of Cooperative Agreements. The Network is designed to investigate problems in adult reproductive medicine, including reproductive endocrinology, obstetrics and gynecology, and andrology.

A member of NICHD program staff acts as Research Coordinator, cooperating with the principal investigators of the selected institutions in identifying research topics of high priority, and in designing and carrying out protocols appropriate to the evaluation of optimum management in these areas.

The first protocol is a trial of infertility treatments in couples with an apparently normal female partner. The design is a 2x2 comparison of intrauterine vs intracervical insemination, each with or without gonadotropin stimulation of the ovaries. Patients are being enrolled at five clinical sites around the country, with data analysis by a Data Coordinating Center.

[Minority supplement] The objective of the ORMH supplement project is to increase recruitment of minority couples into Network protocol studies by developing effective targeted strategies. The investigators will compare the success of traditional recruiting methods, i.e. advertising in newspapers with large minority readership and letters to health care providers in areas with high minority representation, with that of new recruitment techniques such as videotapes, information booths at shopping malls, and luncheon conferences at workplaces and churches.

### **Short and Long Term Implications:**

The Network operates as a collaborating group, as facilitated by the Cooperative Agreement mechanism. Therefore the Network can identify issues with a high degree of objectivity, develop well-designed protocols, provide to participants expert statistical consultation in experimental design and analysis, and provide a large patient base, so that tests and treatments can be evaluated more rapidly and with greater statistical validity than otherwise.



The anticipated efficiency of communication among investigators, and dissemination of information to practitioners and the public, would lead to more effective patient care and more economical use of resources. If new techniques for minority recruitment at Memphis prove useful, they can be quickly shared with the other sites. Increased minority participation will make the findings more relevant and generalizable to minority health.

**Future Events:**

NICHD intends to reissue a request for applications for the Network, which will invite both new and renewal applications. It is anticipated that there will be a twofold emphasis on both infertility and gynecology. Differences in minority populations with respect to patterns of fertility and infertility, and the incidence and manifestations of gynecologic disease, are expected to enter into the planning and design of future network studies.







**"Comprehensive Regional Centers for Minorities" and  
"Partnerships For Minority Student Achievement" Programs**

**Luther S. Williams, Ph.D.  
Assistant Director  
Directorate for Education and Human Resources  
National Science Foundation**

Under a Memorandum of Agreement, the National Science Foundation (NSF) and the National Institutes of Health (NIH) Office of Research on Minority Health are jointly supporting two (2) NSF pre-college programs designed to occasion a major change in participation/performance of racial and ethnic minorities, otherwise underrepresented in science, mathematics, engineering and technology.

The primary goals of the **Comprehensive Regional Centers for Minorities (CRCM)** is to develop systemic approaches to increase the number of minority students enrolling in precollege courses which will prepare them to pursue undergraduate programs in the science, engineering and mathematics (SEM). The projects are focused in regions of high minority populations and are developed through partnerships among several public and private organizations and community groups in the region. The specific objectives of the Center are to implement the following: develop courses and other enrichment activities in elementary and secondary schools; develop and strengthen the capacity to deliver quality instruction in school science and mathematics education; develop interventions that significantly increase minority student enrollment and the successful completion of "gatekeeping" courses; facilitate the successful transition of minority students from high school into undergraduate programs in SEM; stimulate efforts among secondary schools and colleges and universities in the region to development summer enrichment activities and to stimulate efforts among professional organizations, businesses and industries to become involved in mentorship programs for college students. There are currently 14 existing centers and two prototypes serving 4,000 teachers and in excess of 30,000 students participate in CRCM activities.

The goals of **Partnerships for Minority Student Achievement (PMSA)** are to strengthen student SEM literacy, with specific emphasis on expanding the number of underrepresented minority students who enter SEM careers. The objective is to improve minority student achievement in mathematics and science in grades k-12 by expanding student access to and participation in a high quality educational program. With a programmatic thrust on systemic change in school districts/systems, the target population is school systems with a substantial enrollment of underrepresented minority students. Data from the nine implementation projects reveal that better than 100,000 underrepresented minority students are impacted directly or indirectly, along with approximately 2,000 teachers in approximately 100 schools. A robust student database and attendant analyses speak to the utility of these programs in increasing the number and preparation of minority students in K-12 science and mathematics.







## **Minority International Research Training Program**

**David Wolff, Ph.D.**

**Chief, International Research and Awards Branch  
Fogarty International Center**

### **Objectives:**

In October 1992, the Fogarty International Center (FIC) and the Office of Research on Minority Health (ORMH) jointly conducted a workshop to explore "International Opportunities for Minority Students and Scientists" in biomedical and behavioral research. Attendees at the workshop were presidents and faculty of colleges and universities with significant minority enrollments throughout the United States. As an outcome of the workshop the FIC established a new program, the Minority International Research Training Grant (MIRT). The ORMH provided \$3,000,000 to fund awards for FY 1993.

The MIRT program provides international research training opportunities for minority undergraduate students, minority graduate students, and minority faculty members in biomedical and behavioral research. Training grant awards are for three years to U.S. colleges and universities for the purposes of: encouraging minority students to pursue degrees and careers in the biomedical sciences by broadening their undergraduate and graduate education through international experiences; promoting qualities of leadership by expanding cultural perspectives and to help prepare the next generation of scientific leaders to work effectively in a global environment; and establishing linkages between U.S. scientists and institutions and established centers of biomedical research abroad.

There may be any or all of the following three components within each institutional award: first, the international research training program for pre-baccalaureate minority students pursuing life science curricula to conduct short-term research and coursework abroad for approximately 8 to 12 weeks; second, a predoctoral program to enable minority students enrolled in a graduate research degree program to receive research training for approximately 3 to 12 months at foreign institutions; and third, the international faculty development program for individual minority faculty to conduct research at foreign institutions for approximately 3 to 12 months.

Grantees may be individual U.S. institutions or consortia of U.S. institutions with one lead institution. For the purposes of this program, consortia link institutions which have active international programs with those which have limited international connections.

The foreign research centers should be universities, colleges or other research institutions that have strong, well-established biomedical or behavioral research and research training



programs. Close cooperation between the U.S. and foreign institutions and scientists will be needed to provide the trainees with a foreign mentor or collaborator who is recognized as an accomplished investigator and who will participate in their research training.

### **Target Populations:**

Minority participants must be from underrepresented minority groups, including African Americans, Hispanic Americans, Native Americans and Pacific Islanders. The program director at the applicant institution will be responsible for the selection and appointment of participants, selection of the foreign training site(s) and the overall direction of the training program.

Undergraduate student trainees must be pre-baccalaureate, pursuing a relevant biomedical or behavioral science curriculum and must show evidence of a commitment to obtaining a postgraduate research related degree in a biomedical or behavioral field of science. The foreign training for undergraduate students will usually be for approximately 8 to 12 weeks. One faculty person may accompany each group of approximately 4 to 8 minority students and act as a general advisor/mentor during the study abroad. Faculty members serving this purpose are not required to belong to any minority group. They must hold full-time tenure track or tenure faculty positions at the grantee institution, hold a doctoral level degree and have a biomedical research plan to be conducted at the host institution.

Predoctoral students must be enrolled in a U.S. graduate research training program in the biomedical or behavioral sciences. The predoctoral training period may be from approximately 3 to 12 months, for the purpose of learning a technique or carrying out a special project or portion of a project related to their doctoral studies.

The minority faculty development portion of the training grant will provide support for research and studies for approximately 3 to 12 months at a foreign training site. Participants must have regular full-time faculty appointments at the grantee institution or an institution in the consortium. The research plan must indicate the expected benefits of the proposed work.

Students and faculty must be affiliated with a U.S. college or university at the time of selection; however, the affiliation need not be with the grantee institution.

### **Short and Long Term Implications:**

In the next century, the pursuit of science to advance public health will play a key role in the development of national policy and international diplomacy. Public policy decisions on both a national and global scale will increasingly depend on the analysis of scientific data derived from international efforts. The next generation of scientific leaders will need to understand divergent perspectives and cultures, and be able to work and communicate effectively across



national boundaries. As the center of international activity at NIH, the FIC and the MIRT program will play a key role in preparing the next generation of scientists to function effectively in a global environment.

The MIRT program is expected to attract students and scientists in the developmental stages of their education and careers, to increase their awareness of international research opportunities and to acquaint them with the full range of career opportunities in biomedical and behavioral research. Minority faculty members are expected to gain by the foreign research experience in ways that will contribute to the research and teaching programs at their home institution. Their association with the foreign institution will, in many cases, provide future undergraduate and graduate research training sites.

### **Accomplishments in FY 1993:**

Since the MIRT program was recently established, there are no scientific accomplishments to report. The following are the actions taken to initiate the program and make the fiscal year (FY) 1993 awards:

- MIRT program established and program announcement submitted to the NIH Guide on February 26, 1993.
- Database of mailing addresses created; program advertised and information mailed to approximately 3,500 addressees.
- 25 MIRT applications were received by deadline date of May 17, 1993.
- 15 MIRT awards were made in September 1993, each with a 3 year period of support.
- Approximately 150 minority students and faculty will travel abroad to participate in biomedical and behavioral projects, supported by the first year grant awards.

### **Accomplishments in FY 1994:**

MIRT program directors and others attended the first MIRT Network meeting in October, 1993 to inaugurate the program, clarify the administrative and budgetary matters, and to encourage the 15 program directors to interact by sharing experiences and opportunities. Student tracking plans were established.

- The FIC announced a recompetition of the MIRT program with an additional \$3 million from ORMH which will support 12-14 new MIRT grants with 3 year project periods. The application receipt date is March 16, 1994.



**Upcoming Events:**

- The MIRT applications received in FY 1994 are scheduled for a June review by a Division of Research Grants study section and review by the FIC National Advisory Board prior to issuing 12-14 new awards in late August.



## **Minority Adolescent HIV Research Projects**

**Lauren V. Wood, M.D.**  
**Senior Clinical Investigator, Infectious Disease Section**  
**National Cancer Institute**

### **Background:**

Evidence is mounting rapidly that adolescents herald the next wave of the HIV epidemic. The incidence of infection is particularly dramatic in urban minority populations. In the District of Columbia, the AIDS epidemic is escalating at an alarming rate as documented by seroepidemiologic studies which have shown that in certain Washington hospitals:

- 1 out of 47 adolescents is HIV positive
- 1 out of 67 women of childbearing age is HIV positive

The rising rate of HIV transmission among teenagers, increasingly as a consequence of heterosexual activity, has ominous implications for the adolescent population and the dissemination of infection into the population of women of childbearing age and transmission of HIV to their offspring.

The changing fact of the HIV/AIDS pandemic, in which minorities and adolescent/young adult women are increasingly and disproportionately represented, is the major impetus for the Pediatric Branch's development of a comprehensive clinical research program for HIV-infected adolescents. Clinical research trials are needed to investigate the pathophysiology of HIV infection and determine appropriate treatment interventions in the adolescent population. Unfortunately, very few HIV-infected adolescents have been enrolled in research protocols, in part due to lack of protocols geared specifically towards adolescents.

This program is multi-faceted in design and scope and involves clinical research trials investigating comparative antiretroviral pharmacokinetics and Phase I and Phase II studies of investigational agents for HIV infection as well as opportunistic infections. In addition to investigating the pathophysiology of HIV infection and its clinical sequelae, a significant effort will be directed toward extensive psychosocial evaluation of this population and the impact of this disease on the adolescent and his/her family and the ongoing challenge of living with a chronic disease.

The Pediatric Branch will continue to enroll adolescents from all over the United States, with special efforts directed towards targeting adolescents from surrounding local communities, including pregnant HIV-infected adolescent women. Moreover, the program is designed to



facilitate participation in clinical research by historically underrepresented and difficult to engage populations, which include adolescents, minorities and women.

### **Collaborative Goals with the Office of Research on Minority Health:**

Participation by minorities and women in the intramural research programs of the NIH has historically been suboptimal. We view this project as one way to begin to address this issue utilizing the resources and expertise within the Pediatric Branch and the NCI. Despite the wealth of knowledge gained from state of the art bench and clinical research conducted by and services available through the intramural program, the NIH remains an underutilized resource for local health care practitioners and institutions. The Pediatric Branch and the ORMH have identified the following goals, designed to improve the NIH's performance in these areas:

- \* Increase the number of minority HIV-infected adolescents and children enrolled in Pediatric Branch clinical research protocols.
- \* Disseminate information about the biomedical research conducted at the Pediatric Branch, NCI to minority health care providers, local community health clinics and community-based institutions that will assist them in addressing the rising incidence of HIV infection in the minority adolescent and pediatric populations and encourage their participation in research.
- \* Develop a community-based, family-centered, comprehensive care program designed to monitor and enroll HIV-infected adolescents in Phase I or II clinical research trials. The major focus of this program will specifically target pregnant HIV-infected adolescents and their offspring.

### **Community-Based Collaborative Project for Pregnant HIV-Infected Adolescents and Their Offspring:**

In conjunction with ORMH, the Pediatric Branch, NCI has proposed a 3 year collaborative pilot project to treat and enroll District of Columbia adolescents with HIV infection/AIDS in clinical research trials. This pilot program, administered through a community-based health institution, will identify HIV positive adolescents and their HIV-infected children eligible for enrollment in Pediatric Branch research protocols. Access to and enrollment in clinical research trials will be provided in conjunction with comprehensive care and supportive services in this community-based setting.

Adolescents participating in research will undergo inpatients serial pharmacokinetic, pharmacodynamic and immunologic studies, accompanied by intensive healthcare and disease prevention education. this model of intense treatment intervention and education is patterned after successful programs designed for adolescents with chronic illnesses such as asthma and



diabetes. Ongoing research monitoring, clinical care and supportive services would continue on an outpatient basis as mandated by protocol requirements. This pilot project will serve as a national model for developing improved outreach programs designed to officer HIV-positive adolescents **and** their HIV-infected offspring the unique opportunity for access to clinical research and to establish a "family-based" model of comprehensive care for the mother-child dyad.







## **Fourth Biennial-Symposium on Minorities, the Medically Underserved, and Cancer Cultural Diversity, Poverty and Health Care Reform**

### **National Cancer Institute**

#### **Goal of Project:**

The overall goals of this symposium were to exchange the latest scientific information in cancer control among minority and medically underserved populations and to examine strategies for reducing the disproportionate cancer incidence, morbidity and mortality among these groups. Specific objectives were; (1) To advocate the importance of cancer prevention and early detection; (2) to replicate model cancer prevention and control interventions; (3) to understand national health care reform proposals and identify opportunities to participate in the policy formulation process; and (4) to identify needs of these groups and to integrate this knowledge into health care reform policy.

#### **Description:**

Approximately 540 persons attended the conference sessions and many participated in a National Health Care Reform Town Meeting with a Surgeon General Designee. The conference included Minority Biomedical Research Support/Minority Access to Research Career student presentations with cash awards for outstanding student papers. The American Association for the Advancement of Science will publish an edited monograph of the conference proceeding in spring 1994.

Evaluation of the conference program is underway. Participants completed a formal evaluation form for CME credit, and analysis of the rating will be completed within the next few months.

#### **Future Events:**

Anticipated future events include the fifth biennial Symposium which is scheduled for the third week in April 1995. A series of planning meetings for this conference commenced in November 1993.







**McKinley High School  
Adopt-A-School Partnership Program**

**National Cancer Institute (NCI)**

**Purpose of Program:**

The purpose of this Program is to provide state-of-the art enrichment of skills, techniques, knowledge and abilities to the MHS teachers by NCI scientists and professional staff.

**Background of Program:**

The Adopt-A-School Partnership Program between MHS, a Washington D.C. inner city school, and the NCI was implemented during the 1989-1990 school year. This part of the program was to provide a work/learning experience for students from the school. By working with knowledgeable professionals in the NCI laboratories and administrative areas, the teachers gained invaluable experience and knowledge in biomedical research. In addition, the NCI researchers made periodic lectures at the school to those students who worked at the NCI and, or who showed an interest in science. The paid Summer internships at the NCI plus and seminars/lectures during the school year were to increase and improve the students' interest in science.

The NCI Equal Employment Opportunity Committee and the NCI EEO staff became increasingly aware of the lack of similar enrichment for the MHS teachers. Several teachers inquired as to the feasibility of initiating a program for MHS teachers that would accommodate their needs for expansion of knowledge; improvement of skills; and enlightenment of concepts, which by definition is Enrichment.

The NCI designed the Teachers Enrichment Program (TEP) to accommodate those needs. During the Summer of 1990-1991, the (TEP) portion of the Adopt-A-School Program was launched. Three science teachers from the school were provided an opportunity to work in the laboratories along with selected researchers. The researchers/mentors from NCI were selected in accordance with their ability and willingness to train the teachers; their field of expertise; and their general support of the program.

**Target Problem:**

Approximately 50% of inner city high school students drop out of school prior to graduation. Withdrawing from school is the culmination of a deterioration of interest in school months



(and in some cases even years) prior to actually dropping out. Few of those who remain in school consider science or mathematics as a career interest.

The (TEP) program is designed: 1) to impact upon the lack of minorities in the sciences; 2) to increase the high school retention rate of inner city students; 3) to encourage high school students to further their education.

### **Target Population:**

Five (5) McKinley High School Teachers  
Washington, D.C.

### **Operation of Program:**

This joint venture between the NCI and the OMP is in keeping with the goals of the NCI and NIH to increase the awareness of opportunities for minorities.

The 1994 Summer TEP will accommodate five (5) teachers. Opening the program to teachers other than science will exponentially increase the number of students that will be impacted by the Program. Additionally, the program will encourage, support, and advise TEP science teachers to enroll and attend the Howard Hughes Medical Institute. Teachers in other disciplines will be encouraged to participate in training that will improve their classroom knowledge and/or individual careers (e.g. mathematics, communication, etc.).

The NCIE EEO Office will give a group orientation for the teachers prior to entry on duty. Each mentor will hold orientations for his/her teacher on the scheduled entrance-on-duty (EOD) date. Each teacher will follow the general rules and regulations of the specific worksite and NCI procedures. Their work/learn experience will be in congruence with the ability of the teacher to acquire and internalize the information. That information will be individualized and applicable primarily to that specific worksite. As an example, the teacher's experience, education, subject matter and worksite needs will be evaluated for their work/learn assignment. On an individual basis, and at the discretion of the mentor, the teacher may be given the prerogative to o independent research. However, the worksite supervisor is responsible for assignments of work and the general progress of the teacher.

### **Behavioral Results:**

While the direct purpose of the program is to provide enrichment to the teachers from McKinley, the indirect purpose (but equally important) is for those teachers to use that newly acquired information and methodology to teach, motivate, and instill into the students an appreciation of the biomedical sciences and the supportive careers that underpin them. The planned indirect goals will take other forms:



- \* Increase the number of students that consider science as a career
- \* Make students more aware of Life Styles as a source of health
- \* Decrease the rate of drop-out and increase college attendance

**NCI Responsibility:**

- \* NCI is responsible for any financial negotiations involved in the operation of the Program
- \* NCI will select and place teachers with compatible mentors
- \* NCI will make the final evaluation of the Program
- \* NCI will supply personnel for the lectures/seminars
- \* NCI will supply job related equipment and supplies.

**MHS Responsibility:**

- \* MHS will recommend teachers for the Program
- \* MHS will provide space and equipment appropriate for the school site lectures
- \* MHS will disseminate/collect questionnaires provided by NCI from the students/teachers for the evaluation

**Evaluation of Program:**

The TEP will be evaluated prior to the beginning of the next calendar year by means of a written questionnaire and oral interview. NCI staff and MHS teachers will take part in the evaluation. However, it is the intent of the Equal Opportunity Advisory Committee and the project officer to continue the Program for five (5) consecutive years (1990-91 to 1995-96), and then do an extensive five year evaluation which will consist of an annual evaluation and the overall evaluation. The continuation of the program will be determined by the results of the evaluation.







## **Comparative Medicine Program**

### **National Center for Research Resources**

#### **Description of Goals and Objectives of the Program:**

Funds from the ORMH will be used to award supplements to several NRSA institutional training projects currently funded by the Laboratory Animal Sciences Program (LASP), Comparative Medicine Program, NCRR. The purpose of NRSA institutional training grants awarded through the LASP is to make it possible for awardee institutions to select and train individuals for research careers in comparative medicine, laboratory animal medicine, laboratory animal science, and/or comparative pathology. The NRSA program helps to ensure that highly trained scientific manpower will be available in adequate numbers and in appropriate disciplines for the nation's future biomedical and behavioral research programs. The goal of training supported by the LASP is to produce graduates with a basic core of knowledge on comparative medicine, laboratory animal medicine, laboratory animal science, and/or comparative pathology, as well as the skills and motivation to become career participants in biomedical research. Exposure to scientific methodology and research procedures is an essential feature of such training, which provides a strong foundation for trainees to later conduct independent or collaborative research.

#### **Target Population:**

Notification of the ORMH award was made on May 25, 1993. Since it was too late to begin recruitment of minority students for the summer of 1993, each NRSA institutional training program director was queried to see if they had minority veterinary students already selected for the summer who might be supported under this award. Three summer students were identified, as listed below:

<b>Name</b>	<b>Sponsoring Institution</b>	<b>College/University Attended</b>
Malisha Small	Bowman Gray School of Medicine	Kansas State University
Michelle Argersinger	University of MI	Cornell University
Coretta Cosby	University of IL	University of IL







**Minority Clinical Associate Physician (MCAP) Program  
General Clinical Research Centers**

**National Center for Research Resources**

**Background:**

The impetus for establishing the MCAP program was the recognition that relatively small numbers of minority physicians and dentists pursue careers in clinical research. The MCAP application is submitted as a competitive supplement to an existing General Clinical Research Center grant. There are approximately 72 General Clinical Research Centers funded nationwide.

**Collaborative Goals With the Office of Research on Minority Health:**

The MCAP Program shares with the ORMH the goal of increasing the numbers of minorities in the biomedical sciences. Since each recipient of an MCAP award undertakes a clinical research project, it is also possible that such research will ultimately lead to a reduction in the health disparity between majority and minority populations, which is another goal of the ORMH. The ORMH funded two MCAP applications in FY 1993:

- 1) Dr. Celia Mamby at the University of Wisconsin (Madison) who is studying the role of difluoromethylornithine in the suppression of polyamine and ornithine decarboxylase activity in colorectal cancer, and
- 2) Dr. Daryl Cottrell at the Ohio State University College of Medicine who is studying glucose regulation and homeostasis following successful long-term pancreas transplantation in patients with insulin-dependent diabetes mellitus.

**Target Population:**

The target population for the MCAP Program consists of individuals who must have earned the M.D. or D.D.S. degree or equivalent and completed a residency. Completion of a subspecialty (fellowship) training for two years is preferred but not required. The applicant must be a U.S. citizen or hold a permanent visa and should be a member of an underrepresented minority group. An underrepresented minority group is one which has been determined by the grantee institution to be underrepresented in biomedical or behavioral research. In making awards, NIH will give priority to applicants who are Black, Hispanic, Native American, Pacific Islanders, or other ethnic or racial group members who have been found to be underrepresented in biomedical research nationally. The applicant may not hold



independent peer-reviewed grant support as the principal investigator, prior to or concurrently with funding of the MCAP application.

### **Program Description and Objectives:**

The purpose of the MCAP Program is to provide up to three years of support to minority physicians or dentists to promote their development towards becoming independent clinical investigators, under the direction of senior clinical scientist sponsors.

A request for MCAP support is made through a GCRC supplemental application. Research on Center-related projects, performed under the direction of an established investigator (sponsor) must account for at least 80 percent of the time and effort of the MCAP. MCAP applicants who have completed subspecialty (fellowship) training, can request a maximum salary of \$50,000 plus fringe benefits for the first year of the award and salary increments of \$5,000 for each of the second and third years of the award. MCAP applicants with no subspecialty training can request a maximum salary of \$45,000 plus fringe benefits for the first year of the award and salary increments of \$5,000 for each of the second and third years of the award. The salary may be supplemented from other sources, including NIH grants and contracts. The salary request must be commensurate with institutional salary policies for individuals with comparable experience. Funds for small scientific equipment, supplies, and domestic travel to scientific meetings may be requested up to a maximum of \$7,500 per year (domestic travel portion not to exceed \$1,000).

Priorities for funding are based on the scientific merit of the proposal, the qualifications of the applicant, expertise to be gained by the applicant, suitability of the sponsor and the likelihood that the applicant will become an independent investigator capable of successfully competing for independent peer-reviewed grant support.

### **Short and Long Term Implications:**

The short and long term implications are that the MCAP Program provides a vehicle by which minority physicians and dentists may achieve the requisite knowledge and skills to become independent clinical investigators. A well trained cadre of clinical investigators may lead to improvement in the health of the nation.

Since FY 1991, a total of 13 MCAPs have been supported, including the two supported by the ORMH.



Future Events:

The GCRC Program plans to continue the MCAP Program. In addition, the MCAP recipients are invited to attend the annual meeting of GCRC Program Directors and to present their research there.







## **Risk Factors for Gallstone Disease Among American Indians**

### **National Heart, Lung and Blood Institute**

#### **Goals and Objectives of the Program:**

Through the three grants under this project, National Heart Lung and Blood Institute (NHLBI) investigators will involve a large population of Native American patients. investigators will access this patient population to increase substantially our knowledge of gallstones among American Indians through the next examination wave of the Strong Heart Study.

Ultrasonography of the gallbladder will be conducted among approximately 4,000 adult Indians. The prevalence of gallstones will be determined and correlated with the multitude of risk factor data collected in the survey (glucose tolerance test, body circumferences, insulin concentrations, and lipoprotein concentrations).

#### **Target Population:**

Three American indian tribes from Indian communities in Arizona, Oklahoma and the Dakotas who have participated in the Strong Heart Study sponsored by NHLBI.

#### **Accomplishments:**

Gallstones have been reported by investigators to be more common among American Indians than any other ethnic population. In addition, American Indians have the highest incidence of gallbladder cancer in the world, for which the only recognized risk factor is gallstones.

Ultrasound examinations have begun at all sites. Training has been conducted for all ultrasonographers. An ultrasound video tape reading center has been established at George Washington University and is now receiving taps from the field for review. In addition to comparing results across the three Indian communities, we hope to also compare results to the three ethnic groups being examined by ultrasound in the third National Health and Nutrition Examination Survey (White, Black and Mexican American).

#### **Future Events:**

This study will continue to be an interinstitute collaboration, supplementing work that is already in place and taking advantage of a unique opportunity to investigate gallstones and their complications in populations where they are a major health problem.







## **Bridging the Career Gap for Underrepresented Minority Scientists (Symposium)**

### **National Institute of Allergy and Infectious Diseases**

#### **Background:**

The minority research supplement program and other training programs have already identified and begun to train minorities through a variety of funding mechanisms. This cadre of investigators represents the potential "next generation" of minority biomedical researchers.

While they have mentors, established investigators at their research institutions, these individuals have no indication that NIAID maintains a personal and vested interest in their academic future. By establishing a "bridging program" these young investigators could be nurtured and provided an entree to the world of competitive research funding. It was also felt that by bringing these young researchers to Bethesda, we could learn much from their experiences which would help in evaluating the effectiveness of the programs we support, which are designed to increase the number of minorities who are successful in careers in biomedical research.

#### **Collaborative Goals with the ORMH:**

The goal of this symposium was completely consistent with the goals of ORMH in terms of enhancing the participation of underrepresented minorities in successful careers in biomedical research.

#### **Target Population:**

The symposium was targeted towards underrepresented minority investigators currently funded by NIAID under various extramural and intramural training and research programs. These programs include awardees under the Research Supplement for underrepresented Minorities, American Academy of Allergy and Immunology/NIAID/NHLBI allergy and asthma trainees, Intramural Research Training Awardees, etc.

#### **Program Description and Objectives:**

In FY 1993, NIAID developed this new program in which underrepresented minority investigators would be brought to the NIH campus for a two-day seminar entitled "Bridging the Career Gap for Underrepresented Minority Scientists". The objective of the seminar was to allow for the exchange of science; to impart information on applying for research project grants; to acquaint them with the opportunities and options open to them in the field of



biomedical research; and to provide an opportunity to let these young researchers know that the NIAID has a vested interest in their academic future.

The first seminar was held on October 14-15, 1993 and ORMH contributed \$120,000 for logistical support. It was attended by 48 minority investigators, mainly those receiving support from the RSUM program (28) and from the NIAID Division of intramural Research (11). The participation in the program are supported by NIAID awards, which total approximately \$2.6 million.

### **Short and Long Term Implications:**

This seminar focuses primarily on underrepresented minority scientists who are already identified and successful in that they are currently receiving NIAID awards. It seems very reasonable to concentrate on this group to provide additional assistance to ensure that they will be successful in competing for NIAID research grants.

### **Future Events:**

Due to the success of the first "Bridging the Gap" seminar, NIAID plans to continue this program on a biennial basis. It has begun to set in place a tracking system to enable the Institute to follow the progress of these young researchers in the grants system as they begin to submit grant applications. Finally, NIAID is in the process of developing an Internet "bulletin board" to keep the researchers informed of current Institute initiatives in which they might have an interest.



## **Improved Definition of Major Transplantation (HLA) Antigens Characteristic of Hispanics and Native Americans**

### **National Institute of Allergy and Infectious Diseases**

#### **Background:**

Lack of appropriate HLA typing abilities was cited in the Inspector General's report last year concerning racial/ethnic inequities to transplantation. NIAID efforts to identify and improve the definition of HLA antigens characteristic of African Americans have led to the definition of more than 24 new HLA alleles that, to date, have been found only in these populations. These alleles are now part of the standard HLA typing trays used in clinical laboratories for tissue typing and have allowed more African Americans to have better HLA matches. Furthermore, the anticipated knowledge resulting from an upcoming NIAID-supported project to fully HLA type 200 African American families will enhance our ability to specifically define all remaining HLA types specific to this population, thereby eliminating a major road block to transplantation. The focus now turns to an evaluation of transplantation antigens among other populations.

#### **Collaborative Goals with the ORMH:**

This project is consistent with ORMH goals of research and training designed to improve the health of minority populations.

#### **Target Population:**

This research project will focus on HLA antigens of five tribes of Native Americans and Hispanics/Latinos with family origins in Central America, South America, the Caribbean, and Europe.

#### **Program Description and Objectives:**

Since the frequency and distribution of HLA alleles vary among different races, similar efforts previously used among African American subjects can be effectively extended to Hispanic/Latino and Native American populations. The research methods and approaches noted above would be applied to the identification and improved definition of HLA antigens characteristic of Hispanics/Latinos and Native Americans. Such research could be supported through supplemental funding to researchers currently conducting these studies in the African



American subjects. The ultimate goal of this project is to improve the success of organ transplantation in these populations and to better understand those diseases of immune dysfunction which have known HLA associations.

The budget for this project is \$350,000 and it was supported entirely in FY 1993 by ORMH.

**Short and Long Term Implications:**

Improved success of organ transplantation among these populations has considerable short- and long-term consequences.

**Future Events:**

The proposed work plan has been designed and evaluated by a committee of geneticists, anthropologists, and immunologists. Reagents for HLA typing have been assembled and specific Native American tribes are being identified. A workshop on the significance of population differences in HLA antigens was conducted at the 1993 meeting of the American Society for Histocompatibility and Immunogenetics.



## **Studies of Factors influencing Participation of Minority Populations in HIV Vaccine Trials**

### **National Institute of Allergy and Infectious Diseases**

#### **Background:**

Enrollment of individuals from minority groups into Phase I trials of candidate AIDS vaccines in seronegative volunteers has been a long standing goal of the AIDS Vaccine Evaluation Group (AVEG) of the NIAID. However, in spite of the AVEG's efforts, recruitment of minorities has been generally unsuccessful. Of the 332 volunteers who enrolled in FY 1992, 95 percent were white.

The lack of participation of minorities in early vaccine trials could have serious repercussions. The AVEG has recently begun a Phase II trial, the goal of which is to include those populations that have not previously been involved in trials among seronegative individuals, but for whom an AIDS vaccine would be targeted, for example, sexually active inner city young persons who are at risk of infection with HIV. To this end, the AVEG has attempted to recruit volunteers from among those aged 16 to 22 who are attending clinics for sexually transmitted diseases. After several months of intense effort, not one individual from this population has agreed to participate in the trial.

Seven candidate vaccines have been tested by the AVEG since 1988, and all have been found to be safe and immunogenic. However, the vast majority of people who would have received these products have been white, middle class individuals who are at very low risk of becoming infected with HIV. It is unknown what effect the vaccines will have in other groups or what the variation in immune responses between groups may be. The AVEG needs assistance in recruiting from minority populations.

#### **Collaborative Goals with the ORMH:**

This project is consistent with ORMH goals of research and training designed to improve the health of minority populations.

#### **Target Population:**

The vaccine trials of this program will be focused on seronegative individuals from populations who are at greatest risk by the HIV/AIDS epidemic. The main groups sought will be African Americans and Hispanic/Latinos.



### **Program Description and Objectives:**

First, systematic research must be performed to clarify why minorities do not choose to participate in the trials. The few minority individuals who have chosen to volunteer should be surveyed to determine their reasons for participation and their suggestions to improve minority recruitment. Strategies that work/do not work should be evaluated. Second, an extensive effort should be made to educate minority populations about AIDS, ways to prevent infections, and the importance of vaccination in general. The goal, of course, is to prevent transmission of AIDS, but as the populations learn more about the disease, they may be more willing to volunteer for vaccine trials. Third, all of the five AIDS Vaccine Evaluation Units (AVEUs) that comprise the AVEG need assistance with provision of support for recruiters. Each should have at least one recruiter who is a member of the targeted minority population and whose sole efforts are directed towards that population. The goal is to provide peer education, counselling, and ultimately, recruitment for vaccine trials.

The budget for this project was \$468,000. In FY 1993, the ORMH provided \$407,750 in support of this effort. Progress to date includes the following: Minority recruiters are being brought on board at the AVEUs, a video designed to attract minority populations into vaccine trials has been produced, and a subcontract has been let to perform market research on the preparation of recruit materials (video, mailings, handouts and posters) for the recruitment of subjects in low risk HIV vaccine prevention trials. The first focus group, conducted at the St. Louis AVEU, was designed to identify the best group for initial education and dissemination that would result in improved recruitment.

### **Short and Long Term Implications:**

Success to control of the AIDS epidemic resides in the development of an effective vaccine to prevent infection among the seronegative and to possibly treat infection among those already infected. It is crucial that trials of vaccines be performed in populations at greatest risk for infection. At this time, the majority of new AIDS cases occurring annually are diagnosed among individuals from minority groups.

### **Future Events:**

The cornerstone of AIDS treatment and prevention is the vaccine trials. NIAID is totally committed to its vaccine programs, with a goal of beginning large scale trials within the near future. The key to the success of future trials may well reside in the success of efforts supported by this project.



## **Studies on the Use of Directly Observed Therapy for Treatment of Tuberculosis among HIV-Infected Minority Individuals**

### **National Institute of Allergy and Infectious Diseases**

#### **Background:**

The resurgence of tuberculosis (TB) has made it a disease of highest priority for NIAID. In communities hardest hit by this epidemic, especially New York City, HIV-infected persons have experienced the majority of the new cases of this disease. The major risk factors for new cases of TB among patients in the New York area are HIV infection and injection drug use (IDU). The majority of these patients are either African American or Hispanic. Based on the Center for Disease Control and Prevention's (CDC) October 1992 surveillance data, 91 percent of AIDS cases which have IDU as a risk factor belong to these two minority groups.

Significantly complicating the resurgence of TB is the increasing incidence and prevalence of multi-drug resistant isolates of Mycobacterium tuberculosis. According to the CDC, in 1991, 15 percent of isolates were resistant to at least one anti-TB drug, and 3 percent were resistant to the main two drugs (isoniazid and rifampin). Intermittent therapy and poor compliance with drug regimens are widely appreciated as primary factors in the emergency of multi-drug resistant isolates.

#### **Collaborative Goals with the ORMH:**

This project is consistent with ORMH goals of research and training designed to improve the health of minority populations.

#### **Target Population:**

The TB treatment research studies are directed towards the population experiencing the greatest risk of TB, which mainly includes HIV-infected individuals residing in major urban centers of the US, especially New York City. Homelessness and IDU are other prominent risk factors.

#### **Program Description and Objectives:**

One of NIAID's major objectives is to improve therapies to treat TB, with the preclinical and clinical drug evaluation programs receiving highest priorities. However, there are several obstacles to TB research that must be overcome in order to effectively combat this emerging threat to the public health. These include: A lack of investigator interest and involvement



and a lack of interest of the pharmaceutical industry in pursuing the development of new agents to treat or prevent TB. Clinical trials evaluating existing therapies will be expensive because of the large sample size needed to determine efficacy, the length of time needed to complete the studies, and the requirement for Directly observed Therapy (DOT). Under DOT, in order to ensure compliance, health care workers go out and locate patients who fail to keep appointments and actually observe the taking of each scheduled dosage of the medications. This initiative is to augment the support of DOT for studies of TB therapy, mainly in New York City.

The NIAID-supported AIDS Clinical Trials Group (ACTG) and the Terry Bein Community Program for Clinical Research on AIDS (CPCRA) are instituting clinical trials to evaluate potentially effective therapies for the treatment of TB. The limiting factor is the cost of DOT. New York State, through its medicaid reimbursement program for DOT, provides some financial assistance, but the amount is estimated to be considerably less than that needed for support of an individual receiving DOT. DOT can take place at either of three settings, i.e., the clinical trials unit, special centers contracted specifically to provide DOT, or at the methadone maintenance centers.

The CPCRA/ACTG TB treatment protocol, initiated in FY 1993 was designed to enroll a total of 650 patients, with a first year budget of \$977,250. ORMH contributed \$742,250 in FY 93 in support of this project.

#### **Short and Long Term Implications:**

The Ability of a DOT program to control the morbidity and mortality of TB has considerable public health implications. The potential for spread of multi-drug resistant M. tuberculosis by individuals who are not compliance with medication regimens has great implications in terms of legal and ethical societal responsibilities.

#### **Future Events:**

To date, 108 patients have been enrolled in this protocol. It is expected that the total number of patients will be enrolled in 2 years.



## **Minority Student Summer Research Training Program**

### **National Institute Of Dental Research (NIDR)**

This program involves short-term training in research at the University of Rochester for minority students. The program began in 1988 with the objective of attracting qualified minority students into biomedical research careers. Students from dental schools with high minority enrollments throughout the United States are encouraged to apply for the summer program at the University of Rochester. Five participants were selected on the basis of their application, letters of reference, and academic records. An individual from the Office of Minority Affairs at the University devotes a significant amount of time in recruitment and helping trainees with any needs when they are on-site.

The University currently provides five fellowships for the three months of the program to cover the cost of room and board. They also have obtained funding from an industry source to assist trainees with travel expenses. The NIDR provides the trainees with stipends at the rate of \$733 per month for three months. In addition, the Institute provides an institutional allowance of \$125 per trainee per month for three months as well as indirect costs at eight percent of total direct costs.

The program has three components: (1) full-time participation in laboratory research and participation in bi-weekly seminars to share program experiences with other participants, (2) participation in the summer Research Fellowship Program sponsored by the Office of Minority Affairs, and (3) attendance at a monthly seminar series to provide insight into academic career options. Areas in which participants can conduct research under the direct guidance of a mentor include biochemistry, physiology, molecular biology, microbiology, and immunology. Performance of the trainees is evaluated on the basis of their daily performance in the laboratory, their seminar presentation and their overall involvement in the program. Following completion of the program, participants are tracked during the remainder of their dental school careers and efforts are made to facilitate placement in appropriate post-graduate training programs.

The additional funding from ORMH supports four additional trainees, therefore, increasing the number of individuals that can benefit from this very innovative and successful program. The supplement provides for four stipends for three months, an institutional allowance for each trainee for three months, and indirect costs.







**Regional Research Centers  
In Minority Oral Health Program (RRCMOH)**

**National Institute of Dental Research**

This program was introduced in September, 1992 by NIDR to enhance the future competitiveness of minority institutions in the biomedical and behavioral research enterprise. The basic philosophy underlying the program is to link investigators in minority institutions with their counterparts in research-intensive institutions. This program not only focusses research on underrepresented minority populations but also enhances research, in general, in the minority institutions and thus attracts new minority scientists to biomedical and behavioral research.

The objectives of the Centers are to: (1) conduct research to improve the oral health of U.S. racial and ethnic minorities, (2) enhance the research capabilities and participation of members of racial and ethnic minorities in oral health research, and (3) develop and strengthen the minority oral health research infrastructure of minority dental schools serving large minority populations. In addition to these objectives, a faculty development component is an essential part of each center.

The supplemental funds will provide support for the first meeting of the Program Directors and Co-directors of the six centers which is set for September 22,23, 1993 in the Bethesda area. Subsequent annual meetings are planned. The purpose of these meetings is to discuss issues of importance to the successful attainment of program goals and objectives of the RRCMOH as well as to monitor progress in the crucial early stages of development of this program. These meetings also will be valuable in that they will allow for extensive networking among center directors. The funds will cover travel and per diem for thirteen directors and codirectors to attend this meeting.







## **Abnormal Hemoglobin Synthesis -- Mechanism and Detection**

### **National Institute of Arthritis and Musculoskeletal and Skin Diseases**

#### **Background on Issue:**

Homozygous sickle cell anemia is the most common genetic disorder in persons of African origin. The disorders comprise a spectrum of syndromes that ranges from the almost completely benign trait or carrier state, the heterozygote for the genes for beta S and beta A globin genes (AS genotype), to the most severe syndrome, sickle cell anemia, the SS genotype. The cellular basis for red blood cell sickling, intracellular gelation of the hemoglobin S molecule, was found in the 1950s, but it has been only recently that molecular means to disrupt this process, and potentially provide clinical alleviation of the condition, have been found.

#### **Collaborative Goals with the Office on Minority Health:**

This ongoing research project has received supplemental funding from the Office on Minority Health, which has allowed the full range of approved activities to proceed.

#### **Target Population:**

African-Americans with sickle cell disease, and persons with another hemoglobin disorder, thalassemia (Cooley's anemia).

#### **Program Description and Objectives:**

##### **a. DNA Diagnosis of Sickle Cell Anemia and Thalassemia --**

During the past years, rapid progress has been made in the field of prenatal diagnosis of sickle cell anemia and thalassemia as a result of the introduction of the polymerase chain reaction (PCR) and nonradioactive methods. Many centers of prenatal diagnosis have set up this approach. However, research for even simpler methods are necessary as DNA tests are gradually being transferred from research to clinical settings, and as sickle cell anemia and thalassemia are found in many developing countries where simple and nonradioactive techniques are mandatory. The University of California, San Francisco laboratory of Dr. Y. W. Kan has tested several nonradioactive methods. He believes that the simplest one to date is based on the principle of reverse dot blot. In this procedure, oligonucleotides corresponding to the normal and abnormal sequences are immobilized on nylon filters. The test DNA is then amplified in the presence of biotin, hybridized to the oligonucleotides on the filters, and detected with horseradish peroxidase or alkaline phosphatase reactions. Using this approach,



Dr. Kan has now developed procedures for some of the common mutations in the Mediterranean, Chinese, and American Black populations. Development of probes for these mutations would greatly enhance the ability to use DNA diagnosis for thalassemia and sickle cell anemia around the world.

DNA analysis in the fetus now depends on the established method of amniocentesis or on chorionic villus biopsy. Both of these procedures, though low risk, involve the invasion of amniotic cavity or fetal decidual tissues. Theoretically, a noninvasive method, risk-free for the fetus, would be provided if it is possible to isolate fetal cells from the maternal blood. It has been established in several laboratories that fetal cells, although extremely low in number, could be found in maternal circulation even in early gestation. The problem lies in the ability to isolate these fetal cells. Because fetal cells are extremely rare in the maternal circulation, great difficulties are being encountered in the isolation of a pure fetal cell population for analysis. Furthermore, these separation procedures require expensive equipment as well as labor-intensive procedures. Therefore, Dr. Kan is devising a novel and simple approach of isolating fetal cells. The principle is to utilize a gradient to separate nucleated cells from maternal blood and then to use immuno-fluorescent stains to identify nucleated red cells that produce embryonic hemoglobin. His preliminary experiments show that he can easily obtain enough DNA for analysis following PCR with as few as 25 cells. This method's simplicity may make it widely applicable in many centers and in many countries for prenatal diagnosis of sickle cell anemia and thalassemia.

**b. Control of Globin Gene Expression --**

Other investigators have shown that butyrate stimulates fetal hemoglobin synthesis in erythroid cell culture. Infusion of butyrates into fetal lambs delays or inhibits the fetal to adult globin switch. Recent human trials showed that this compound may elevate fetal hemoglobin in patients with sickle cell anemia or thalassemia. In collaboration with these investigators, Dr. Kan plans to perform experiments on the patients' nucleated red cells before and after treatment with butyrate, with the aim of detecting changes in the hemoglobins following butyrate treatment in order to reveal protein-DNA interactions which may be associated with fetal hemoglobin induction. He will then study the nature of these proteins, with the intent to define better drugs for influencing fetal hemoglobin synthesis for the treatment of sickle cell disease patients.

**Short and Long Term Implications:**

Much additional information is being gained about the molecular basis of sickle cell anemia, and vast improvements in the ability to provide genetic counselling already have been derived from the work of Dr. Kan. Further gains are envisioned. In addition, the work may lead to the development of a new drug, which may provide clinical relief from the symptoms of sickle cell disease.



**Future Events:**

Additional studies are planned on the molecular control of the hemoglobin gene.







## **Minority Recruitment and Training Program**

### **Addiction Research Center National Institute of Drug Abuse**

#### **Background on Issue:**

The National Institutes of Health (NIH), National Institute on Drug Abuse (NIDA), Addiction Research Center (ARC) implemented the Minority Recruitment and Training Program (MRTP) in 1991. The central theme of the program has been the Changing Face of Science and the major purpose has been increasing the participation of presently underrepresented minority groups in the wide spectrum of biomedical and other sciences in addiction research. MRTP is modelled after the major scientific thrusts of NIH, NIDA, and the ARC to provide equivalent priority status to recruitment and training of minority students and faculty with interest in science and assure mechanisms for program maintenance, regular review of program quality, and productivity.

#### **Collaborative Goals with the Office of Research on Minority Health (ORMH):**

Specifically, we contend that persons from presently underrepresented populations must be trained in all aspects of addiction if the disparate negative health consequences of drug abuse are to be reduced and eliminated in minority populations. Themes and goals of the ARC MRTP parallel those of NIDA, and align with the NIH strategic plan and the ORMH mission of increasing the number of minorities in the biomedical sciences and reducing the health disparities between majority and minority populations.

#### **Target Population:**

The target population is composed of minority middle school through high school students, undergraduate and graduate students, medical students, and junior and senior college and university faculty in the biomedical and behavioral sciences.

#### **Program Description and Objectives:**

MRTP comprises special project initiatives designed to have a broad but integrated influence on reducing the burden of drug abuse among minorities. Major projects are the *Summer Fellowship for Minority College/University Faculty*, *Minority Research Supplement/Summer Initiatives*, and the *ARC School Science Fair*.



The Summer Fellowship for Minority College/University Faculty project provides research fellowship positions that allow college/faculty from Historically Black Colleges and Universities (HBCUs), Other Equal Opportunity Educational Colleges and Universities (OEOECUs), and institutions with significant minority enrollments to conduct research in the NIDA ARC Intramural Sections and Laboratories during summer recess. The objective is to have faculty participate in the design, conduct, and analyses of biomedical and behavioral sciences research related to drug abuse.

*Minority Research Supplement/Summer Initiatives* provides supplements for increased minority participation in traditional ARC Summer Student Fellowships. The project is intended to enlarge minority participation in training opportunities for students who are interested in the scientific basis of drug dependence. Research exposure, projects or collaborations are structured and implemented. Ongoing ARC seminar participation is encouraged. Awards are for the equivalent of six-to-eight weeks or one-quarter or semester.

*The ARC School Science Fair* is an Addiction Research Center cosponsored science demonstration, one-day fair for students in the Baltimore City School system. The purpose of the fair is to provide a unique exposure and introduction to science for minority elementary and/or high school students who traditionally lack this exposure.

### **Short and Long Term Implications:**

*Summer Fellowships for Minority College/University Faculty* enables participants to transmit the excitement of research as well as newly learned concepts to their students. This project facilitates the efforts of these faculty to establish programs of research in their home institutions. Diverse expertise of persons with experience teaching theoretical, analytical, social, and clinical sciences related to enlargement of understanding, prevention, and treatment of drug abuse among minorities is also obtained. The purpose of the ARC School Science Fair and the Summer Initiative is to provide learning experiences for minority middle school through high school students, undergraduate and graduate students, and medical students to raise their level of consciousness about addiction research, preventing, and treatment availability; to increase knowledge about drug use; and to provide a model of professionalism.

### **Future Events:**

ARC MRTP will award at least 3 *Summer Fellowships for Minority College/University Faculty* and least 6 Minority Research Supplements during the summer of 1994. Plans were outlined in 1993 for the ARC School Science Fair being co-sponsored by the ARC and Coppin State College in Baltimore, Maryland. The fair will be held on April 29, 1994 at the Percy Julian Science Center on the grounds of Coppin State College in conjunction with the College's Eighth Annual Substance Abuse Conference, "The Community and Higher



Education Solving the Drug Abuse Problem." The ARC remains committed to providing scientists to man the exhibits and demonstrations and paying the costs of box lunches and local transportation of all equipment used by the six Branches and Laboratories that will be participating in the Fair. Approximately 250 minority students representing the sixth through eighth grades will be in attendance. This spring, meetings will be held with representatives of Morgan State College to include this institution as a cosponsor for another fair in 1995.







## **Predoctoral Fellowship Awards for Minority Students**

### **National Institute of General Medical Sciences**

#### **Purpose:**

The intent of this Minority Predoctoral Fellowship Program is to make graduate fellowships available to underrepresented minority graduates from all institutions, including the many minority undergraduate students who have participated in the various NIH-sponsored programs to prepare them for research careers. This program is designed to encourage greater numbers of underrepresented minorities to pursue graduate degrees, thus fulfilling the goal of increasing the number of minorities trained for careers in biomedical research.

#### **Program Description:**

The National Institute of General Medical Sciences (NIGMS) is accepting applications for individual National Research Service Award (NRSA) Predoctoral Fellowships for Minority Students. These fellowships will provide up to 5 years of support for research training leading to either the Ph.D. degree or the combined M.D./Ph.D. or other combined professional doctorate/research Ph.D. degrees in the biomedical sciences for highly qualified students from minority groups found to be underrepresented in the biomedical and behavioral sciences. Support is NOT available for individuals enrolled in medical or other professional schools UNLESS they are enrolled in a combined professional doctorate/Ph.D. degree program in biomedical research.

The fellowship award provides an annual stipend of \$8800, or current level, to help meet the fellow's living expenses; a tuition and fee allowance in accordance with NIH policy; and an annual institutional allowance of \$2000, which may be used for travel to scientific meetings and for laboratory and other training expenses.

#### **Upcoming Events:**

For FY 1994, it is anticipated that at least 50 new fellowship awards will be made, if sufficient numbers of high quality applications are received. The NIGMS will be joined by the following awarding components of the NIH in providing funds to support this program: the National Institute on Aging, the National Institute on Alcohol Abuse and Alcoholism, the National Institute of Allergy and Infectious Diseases, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Cancer Institute, the National Institute of Child Health and Human Development, the National Institute on Deafness and Other



Communicative Disorders, The National Institute of Dental Research, The National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute on Drug Abuse, the National Institute on Environmental Health Sciences, the National Eye Institute, the National Heart, Lung and Blood Institute, the National Institute of Mental Health, the National Institute of Neurological Disorders and Stroke, the National Library of Medicine, and the National Center for Research Resources.



## **Biomedical Science Career Orientation for Minority Students (BSCOMS)**

### **Office of Equal Opportunity The National Institutes of Health**

#### **Background on Issue:**

As an action item in the NIH OEO multiyear Affirmative Employment Programs Initiatives, the OEO proposed to coordinate a program which utilized technical work experience and communication in a scientific environment to create interest and a challenge for minority students in Biomedical Research. Such an opportunity existed with the District of Columbia METropolitan CONsortium (**METCON**) for Minorities in Engineering, Inc., and the Howard University's School of Engineering.

**METCON** coordinates engineering and scientific resources from local industries, community organizations, school systems, engineering schools, private firms, government agencies, volunteers, professional and community groups in the Washington, D.C. metropolitan area. This coordinated network provides for the delivery of technical resources to elementary, junior high, middle, and senior high schools. **METCON** is incorporated in the District of Columbia as a nonprofit organization. The **METCON** office is located at the Howard University's School of Engineering which uniquely enables **METCON** to provide the administration expertise required to implement the program.

#### **Collaborative Goals with the Office of Research on Minority Health:**

The Office of Equal Opportunity in conjunction with **METCON** developed a proposal to initiate a science career orientation pilot program at NIH, by linking up with Howard University, since their program was extremely successful at NASA, EPA, NOAA, and NSF. The Director, Office of Research on Minority Health funded the pilot program and BSCOMS effected in June 1992.

The NIH pilot program was highly successful based on the evaluations and assessments conducted at the end of the program and the program was funded for a second year. The NIH has committed to provide funds for BSCOMS, thereby making it one of its regular, ongoing programs for minority students.



**Target Population:**

Minority High School Students, grades 11 and 12, who have demonstrated an interest in science and research through their academic achievement in the science classes and their participation in the **METCON** Clubs at their respective schools.

**Program Description and Objectives:**

The BSCOMS is a career orientation program whose purpose is to encourage minority students to pursue scientific careers. The objectives of BSCOMS are to:

- \*expose high school students from groups traditionally underrepresented in science to state-of-the-art biomedical research. It is expected that students will enhance their interest and understanding of science and, from this experience, develop conceptual and technical skills relevant to the scientific enterprise;

- \*make students aware of career opportunities in scientific occupations;

- \*expose students to the work of NIH scientists; and

- \*provide opportunities for students to develop scientific report writing and oral presentation skills.

**Short and Long Term Implications:**

Short Term: a large number of minority students will be exposed to biomedical research and the career opportunities in scientific occupations;

Long Term: an increase in the number of minority students pursuing scientific careers in biomedical research.

**Future Events:**

Increase the number of students participating in BSCOMS.















**U.S. Department of Health and Human Services**  
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Office of Research on Minority Health